



HAL
open science

Termination of pregnancy for foetal indication in the French context analysis of decision-making in a Multidisciplinary Centre For Prenatal Diagnosis

S. Baumann, Sylviane Darquy, C. Miry, N. Duchange, G. Moutel

► **To cite this version:**

S. Baumann, Sylviane Darquy, C. Miry, N. Duchange, G. Moutel. Termination of pregnancy for foetal indication in the French context analysis of decision-making in a Multidisciplinary Centre For Prenatal Diagnosis. *Journal of Gynecology Obstetrics and Human Reproduction*, 2021, 50 (8), pp.102067. 10.1016/j.jogoh.2021.102067 . hal-03154723

HAL Id: hal-03154723

<https://hal.science/hal-03154723>

Submitted on 13 Feb 2023

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.



Distributed under a Creative Commons Attribution - NonCommercial 4.0 International License

Title: Termination of pregnancy for foetal indication in the French context

Analysis of decision-making in a Multidisciplinary Centre for Prenatal Diagnosis

Running title: Decision-making in a French MCPD

Word count abstract: 186

Word count text: 3274

Tables: 4

Authors: Sophie Baumann¹, Sylviane Darquy², Claire Miry³, Nathalie Duchange¹, Grégoire Moutel^{1,4}

Author's institutional affiliations:

¹ Normandie univ, UNICAEN, Inserm U1086, ANTICIPE, 14000 Caen, France

² Univ. Bordeaux, Inserm U1219, EPICENE, Cancer et expositions environnementales, 33000 Bordeaux, France

³ Hôpital Universitaire de Strasbourg, Service de Médecine fœtale 67091 Strasbourg cedex, France

⁴ Espace régional d'éthique, CHU de Caen, Normandie Université, 14000 Caen, France

Corresponding author at :

Darquy Sylviane

Université de Bordeaux - Inserm U1219, Equipe EpiCEnE

146 rue Léo Saignat

33076 BORDEAUX Cedex, France

Email : silviane.darquy@u-bordeaux.fr

Conflict of interest statement

The authors have no conflict of interest to declare.

Highlights

What's already known about this topic?

MCPD activity is reported annually in statistical results by the French biomedical agency: number of acceptances and refusals, broad categories of indications.

What does this study add?

- The indications for foetal termination of pregnancy in a French MCPD
- The professionals' perspectives on their practice: the more complex decisions become in the field of antenatal diagnosis, the more professionals value collegiality within these structures.

Abstract

Objective: In France, termination of pregnancy (TOP) for medical reasons is legal, regardless of the term, after authorisation by a Multidisciplinary Centre for Prenatal Diagnosis (MCPD). This study analyses the elements supporting the TOP decision-making process faced with a foetal pathology.

Study design: Medical records of one MCPD were analysed for the period 2013 and 2014 and semi-structured interviews with MCPD members were conducted.

Results: Out of 265 files concerning foetal indications, all but one resulted in a decision for TOP. The main indications in number for TOP were malformations and chromosomal abnormalities. For indications such as trisomy 21, authorisations are generally given without discussion. Our results underline the importance that professionals attach to the collegiality of decisions, particularly in situations of uncertainty.

Conclusion: This study provides information about the activity of MCPDs within the field of prenatal diagnosis and shows the importance of these structures in supporting women and couples whilst respecting their autonomy. At present, the role of the MCPD is in the process of evolving and could become an information and advisory board for women, based on collegial expertise to guide their decision-making.

Key words: termination of pregnancy for foetal anomaly (TOPFA); prenatal diagnosis; collegiality; particular severity; decision-making

Introduction

2 Medical and technical advances in prenatal care have made prenatal diagnosis increasingly
possible for a continually lengthening list of abnormalities presenting various levels of
4 severity, with sometimes-uncertain prognosis [1,2]. Meanwhile, therapeutic capabilities
have not increased to the same degree, leading to the difficult situation of choosing
6 between continuation of pregnancy and abortion. Most developed countries have some
form of prenatal screening for Down syndrome and other major foetal anomalies [3,4].
8 Legislations and practices vary from one country to another, but prenatal diagnosis and
termination of pregnancy for foetal anomaly (TOPFA) raise important ethical dilemmas
10 everywhere in the world [5,6].

In France, termination of pregnancy (TOP) has been legal since 1975 [7] and has been
12 allowed without medical indication up to 14 weeks since 2001: “After this time period, a
medical reason is necessary and abortion can be performed at any time [...] if there is a
14 strong probability that the child to be born has a particularly severe disorder, recognised as
incurable at the time of diagnosis” [8].

16 TOP for medical reasons is performed at the mother’s request after examination by a
Multidisciplinary Centre for Prenatal Diagnosis (MCPD). These Centres were established by
18 the French bioethics law of 1994 and have been operating since 1999. Their mission is to
assist medical teams and couples in the analysis, decision-making and follow-up of
20 pregnancy when foetal anomaly is detected or suspected [9]. After collegial discussion, they
issue a TOP authorisation on medical grounds by certifying the seriousness of the situation.
22 However, a decree of June 2015 states: “The autonomy of pregnant women is a
fundamental principle in prenatal diagnosis. Her will and choices are at the core of the
24 MCPD process and functioning”[10].

The cross expertise of different specialists and their plurality of values are at the heart of the
26 *modus operandi* of MCPDs. Their members take into account the nature and degree of the
pathology, the possible treatment modalities as well as the specific situation and familial
28 environment. The process ensures the transparency of reasoned decisions as well as
traceability. A MCPD comprises gynaecologists and obstetricians, paediatricians, geneticists,
30 sonographers, radiologists, paediatric surgeons, midwives, psychiatrists or psychologists and
genetic counsellors. It must also ensure the collaboration of other specialists such as foetal
32 pathologists or biologists specialised in foetal abnormalities. It meets regularly, on a weekly
basis, and functions through a collegial decision-making procedure. If the MCPD agrees, two
34 physicians who are members of this MCPD must still ratify the decision, and the cost of the
TOPFA is borne by the national health insurance. To date, there are 49 MCPDs throughout
36 the French territory.

The rate of acceptance of TOPFA by MCPDs has remained stable over the last 5 years in
38 relation to applications. In 2010, 6949 particular severity statements for TOPFA acceptance
and 119 refusals were recorded, and in 2015, 7084 applications were accepted and 132
40 refused; the acceptance percentage remains around 98.5% [11].

The objective of this study is to consider the decision-making process within MCPDs. First,
42 we analysed the elements supporting the professionals' decision to accept or refuse a TOP.
Second, we investigate MCPD members' vision about their role, and how they interpret the
44 concept of particular severity according to the law. Finally, we explored their view on the
evolution of diagnostic tools.

46 **Methods**

This study (file analysis and interviews) was carried out in 2015.

48 *Files Analysis*

This study consisted of a review of all TOPFA applications submitted to one MCPD selected
50 for its high level of activity and number of files studied each year. Files for the two
consecutive years of 2013 and 2014 were studied. The following elements were gathered:
52 indications of TOP; number of presentations to MCPD; time between application and
performance of TOP.

54 *Semi-structured interviews with MCPD members*

All MCPD professionals regularly present at MCPD meetings were contacted and eight
56 accepted to be interviewed: three obstetricians, three midwives, one psychologist and one
geneticist (five women and three men). No paediatrician accepted to participate.

58 Each interview lasted between 20 and 30 minutes and was recorded with the agreement of
the professional. The main themes explored were TOPFA for Down syndrome; the notion of
60 "particular gravity, serious disease or condition" in situations of uncertainty; the principle of
women's autonomy; and collegiality. A qualitative analysis was performed from the
62 transcription of the interviews.

Ethical background: Data collection was strictly anonymous in accordance with medical
64 secrecy; a person from the healthcare team carried out anonymisation.

Results

66 *Medical records analysis*

We reviewed 280 files submitted to the MCPD for the period 2013-14. Fifteen files were not
68 included because they concerned maternal indications of TOP. Thus, 265 cases fell within
our objectives of foetal indications. All but one (i.e. 264) resulted in a TOP acceptance. The
70 refusal concerned a case of mosaic Klinefelter syndrome.

Table 1 presents the indications of TOP for all 264 applications authorised by the MCPD. The
72 majority correspond to malformations without chromosomal abnormalities that are
classified according to the body regions affected. Chromosomal abnormalities also represent

74 a high number of cases among which trisomy 21, which is responsible for Down syndrome,
accounts for more than half of cases. Less frequently, indications correspond to genetic
76 disorders, infections or other unclassified situations.

Table 2 presents the number of times files were presented to MCPD meetings. Depending on
78 the indications, the cases required one or more meetings to reach the decision.

In 203 cases out of the 264, the decision was reached in one meeting. Among them, 107
80 corresponded to chromosomal indications detected during the first half of the pregnancy:
trisomy 21 for the majority (n=64); trisomy 18 (n=19); trisomy 13 (n=10); Turner's syndromes
82 (n=8); and others (n=6). Decisions reached in one meeting were found for 75 of the 123
indications of malformations, 11 of the 13 indications of genetic diseases, 2 of the 3
84 indications of foetal infections, and 8 of the 10 other unclassified indications.

In 61 cases, consecutive meetings two to three weeks apart were required to reach the
86 decision. They corresponded to 48 malformations, 8 chromosomal abnormalities, 2 genetic
disorders, 1 infection and 2 other indications.

88 When files were presented several times, the opinion of an organ specialist or new imaging
exploration was required. The mean gestational age at TOPFA was delayed from 16 to 24
90 weeks of gestation (wg) according to the number of presentations in MCPD meetings (Table
2). An analysis of the records shows that all women received at least one ultrasound and
92 chromosomal analysis and a discussion with their obstetrician.

The term for carrying out TOPFA varies greatly: it extends throughout the pregnancy (Table
94 3) and depends on the number of MCPD presentations and on abnormalities. The majority
are performed before 21 wg, but 5.7% are carried out after 30 wg. The average time elapsed
96 between the decision at the MCPD and TOP is 6.6 days and this period is often reduced at
the request of the parental couple, especially in cases of trisomy 21 and 13 (5.4 days).

98

100 *Semi-structured interviews with professionals* (Table 4)

Consensus concerning Down syndrome

102 All the professionals interviewed confirm the decision-making consensus regarding Down
syndrome and the lack of debate around this indication. Most of them explain that the fact
104 of carrying out a systematic prenatal screening is a choice of society. By setting up this
screening, the French legislator initiates a list of foetal TOPs' indications leading to
106 consensual and "automatic" acceptance of TOP requests for Down syndrome. For this
pathology, our study shows that the period of implementation of TOP is the shortest (under
108 one week).

In addition, seven of the eight professionals question the lack of research, care and
110 acceptance of children with Down syndrome, unlike in other countries, especially in Europe
where these children and adults are better accepted and integrated into the school and
112 professional communities.

Situations of uncertainty and notion of particular severity

114 All professionals reported that some indications are still debated within the MCPD due to
prognostic uncertainty. The most exemplary case is corpus callosum agenesis. Regarding this
116 disorder, some point out an evolution in diagnosis leading to a decrease in TOP over the last
15 years. They emphasised that more powerful diagnostic tools would reduce the degree of
118 uncertainty.

All agreed that the concept of "high probability" is difficult to determine. In their opinion,
120 face to the probability of a potential severe clinical picture, couples have full legitimacy to
decide.

122 As regards the concept of a “particularly severe” disorder, most professionals do not believe
124 that a list of foetal anomalies creating a right to TOP should be drawn up because new
therapies, particularly in genetics, will change the vision of some disorders in the future.

126 *Role of MCPDs in relation to women’s autonomy*

The professionals recalled that the legal framework is based on women’s autonomy. They
128 are also concerned by their role in protecting the foetus, especially in the event of a
disability that is viable or accessible for treatment. Professionals all focused on the ability of
130 MCPD to refuse TOP if necessary, especially in the event of a disability that is viable or
accessible for treatment. However, their responses show that they are aware of the fragility
132 of the legitimacy of the MCPD. Several stated that they are not opposed to those couples
asking for a second opinion from another MCPD in case of a first refusal. They all recall
134 situations in which women were forced to continue their pregnancy, leading to severe
postpartum depression, with all the harmful and possibly irreversible consequences on the
136 mother-child bond.

About collegiality

138 The decision of the MCPD relies on the principle of collegiality, defined in this case as multi-
professional expertise. All the interviewees stated that they are convinced of the importance
140 of this collegiality for themselves, but also for women and couples: also, each professional
has his own position on what he considers important. This system provides support for
142 professionals and helps reassure them because a mistake is always possible. Professionals
also think that it is important and reassuring for couples because of the guilt experienced
144 with termination of pregnancy. Finally, a midwife pointed out that the presence of an
ethicist or philosopher would sometimes be a plus to take a step back from some complex
146 cases.

148 **Discussion**

150 Since the introduction of MCPDs, few studies have investigated their functioning and the contribution of these centres to antenatal diagnosis and support for couples. Our results show that unfavourable opinions are exceptional. They represent one refusal out of 265 requests (0.37%). This tallies with the national percentage, with ranges from 0.24% to 0.31% of the files for the period 2011 to 2015, as reported by the French biomedicine agency [11].

154 This underlines the fact that files submitted to MCPDs following couples' requests are the result of high-quality evaluation by clinicians and constructive discussion with couples. This leads to a better targeting of files presented to MCPDs. Malformations considered as not severe and able to benefit from surgery are referred directly to an adapted care pathway. In contrast, severe malformations are examined by the MCPD and usually lead to an acceptance of interruption.

160 In our study, the majority of TOP indications are the result of pathologies of particular severity, recognised as incurable at the time of diagnosis. The main indications for TOP found in the medical records were malformations without chromosomal abnormality and chromosomal abnormalities with or without associated ultrasound anomaly. These represent the main indications at the national level, as shown in a 2010 study by Dommergues *et al.* [12] where the indications for TOP from 48 MCPDs were reported.

166 A number of chromosomal abnormalities such as trisomy 21 or trisomy 18 are paradigmatic examples of indications where the decisions have become consensual between MCPD members and other specialists. Since the prenatal screening model and management for trisomy 21 became the norm, the consequence has implicitly been an automatic acceptance of the principle of TOPFA. The legislation governing prenatal diagnosis requires that every pregnant woman has to be informed of the existence of trisomy 21 screening. It also

172 requires information to be given on the possibility of revealing other potentially identifiable
conditions. This obligation to inform can be seen as a strong incentive for screening and
174 termination of pregnancy in the event of abnormalities [13,14]. For these indications,
decisions are made within one meeting, generally.

176 For some malformations and some chromosomal abnormalities, diagnostic uncertainties or
late detection require several meetings, usually one to three weeks apart, to better explore
178 the situation. Decisions are particularly critical when the viability threshold is reached.

Indeed, the number of pregnancies with a foetal pathology that would previously have given
180 rise to a TOP and that have been continued increased between 2011 (762) and 2015 (1296).

For some well-defined pathologies, treatment protocols, most often surgical, are
182 established. For others for which there is not necessarily a surgical indication, it is mainly a
question of ensuring medical care from birth, deciding on the conditions of birth and
184 preventing certain complications by organising paediatric follow-up.

Following TOP authorisation, the discussion continues between the woman and the clinician,
186 to allow a period of reflection and maturation of the decision. The medical teams are in
favour of a reflection period of not less 6 to 7 days, as recommended by law. Couples usually
188 want things to go fast. For professionals, the importance not to rush is essential to give to
couples the time to accept the end of the pregnancy and the loss of the future child.

190 However, our results show that for some pathologies such as trisomy 21 and trisomy 13, the
period is reduced according to the decisions of women and couples (see comments in Table
192 4).

What about a list of pathologies?

194 The advisability of drawing up an official list of pathologies that would lead to TOP in the
framework of the law has been strongly debated. Such a list would give the practitioner the

196 security of knowing they were acting within a framework accepted by peers. It could on the
other hand put pressure on doctors to adhere to that list [15].

198 The spirit of the French law is to leave discussion on a case-by-case basis, and there are a
number of arguments against the establishment of such a list. First, the particular severity of
200 a situation has to be estimated on an individual basis, relying on medical expertise and on
the familial context. Second, the risk of drawing up a list of pathologies would be able to
202 make TOPFA systematic. Then, It would **be** then transition from possibility to compulsory,
thus contributing to an eugenic trend [16,17]. The risk would be a norm of decisions and an
204 absence of discussion leading to an erosion of informed decision-making [18]. Furthermore,
for the same pathology, the prognosis may differ from one individual to another; as
206 diaphragmatic hernia.

Finally, updating this list with the evolution of knowledge and treatment seems difficult [15].

208 To date, genome research technologies allow to refine the prognosis of some
malformations, such as agenesis of corpus callosum for example. At present the possibility of
210 carrying out prenatal diagnoses of genetic diseases with late onset (hereditary cancer) raises
ethical issues [19, 20].

212 In France, the evaluation of conditions of particular severity is collegial within MCPDs. Our
results underline the importance that professionals attach to this structure and to the
214 collegiality of decisions. Through the MCPD process, professionals agree that they do not
have the task of imposing their own opinion and that the decision is based on collective and
216 shared validation. In France, the biomedicine agency clearly—specifies the methods for
recording decisions and their traceability [21].

218 Considering the emergence of medical practices, such as voluntary termination of pregnancy
and assisted reproductive technologies, the legislator has established In article 16 of the
220 French Civil Code, the principle of "respect for the human being from the beginning of his or

her life [22]. (Thus, the conceived child is not a "legal person", it is a "human person". It is
222 this distinction which makes it possible to put in place abortion regimes based on women's
freedom. It is clear that the desire of the woman and the couple is largely taken into
224 account since the majority of requests are accepted. The professionals recalled that the
legal framework is based on women's autonomy and among the amendments to the law on
226 bioethics, TOP was introduced for "psychosocial distress", an act that can be carried out
almost up to the end of the pregnancy [23].

228 What evolution and place for MCPDs to come?

Will it still be up to the medical profession in the future to decide what handicap or risk is
230 acceptable or not for couples? This question is all the more topical as professionals perceive
possible shifts in the years to come, particularly because of the advent of non-invasive
232 technologies and the potential to analyse the full genome. Today, non-invasive prenatal
diagnosis (NIPD) allows the detection of genetic abnormalities targeted to trisomy 21 and
234 other genomic anomalies at an early stage [24-26]. This test will be covered by the health
insurance in France.-This may lead to the emergence of interruption requests for a number
236 of pathological predispositions.

There are currently debates about the conditions under which this test can be used, in
238 particular for predictive risk markers of disorders such as cancer [20, 27]. It is anticipated
that, in the event of a result with potential risk, parents' and health professionals'
240 preferences may be different. The latter may be "subjected" to pressure further to women's
requests [28].

242 These ongoing developments [29] will lead to questions surrounding the role and missions of
the MCPDs in coming years. As NIPD can be performed at an early stage, ultrasound is
244 completed, this will allow for the opportunity of abortion within the legal timeframe of
pregnancy interruption without evaluation by a MCPD.

246 Under French law, this timeframe is 14 weeks of amenorrhea, but an extension of the legal
delay to 16 weeks of amenorrhea is currently debated. Before this deadline, some couples
248 may opt for abortion, even when doctors consider the risk of illness low or the potential
“anomaly” of low severity. NIPD may also open up the possibility of sex selection of the
250 future child or access to genetic testing for other markers of pathologies as well as
determining risk factors, broadening the debate [30-32]. While respecting women’s and
252 couples’ autonomy, it will be important to evaluate and monitor the quality of the
information delivered to women and their understanding of the issues at stake.

254 In this context, the advisory role of the MCPD would be enhanced, based on collegial
expertise to guide women in their decision-making. Limits of the study. The present work
256 was performed five years ago in one MCPD. It is important to emphasise that within the
legal framework, MCPDs may have different organisational modalities. However, the data
258 collected from the medical files in this study reflect those collected at the national level by
the French agency of biomedicine, justifying the interest of this study. The interest of our
260 study also lies in the qualitative approach to the experience of professionals.

262 ***Conclusion***

The decision-making process in the MCPD is based on discussion and multi-professional
264 collegiality faced to complex choices. The analysis of the files and the approach of the
professionals by interview showed how the latter take into account, on the one hand, the
266 interest of the foetus and, on the other hand, the expectations of women and couples. How
couples envision future possibilities for their unborn child remains a challenge. This study
268 provides information about the place and the role of MCPDs within the field of prenatal
diagnosis. These structures are essential in supporting women and couples whilst respecting
270 their autonomy.

272 **Acknowledgments**

The authors thank all the MCPD staff for their help in the study of medical files and MCPD

274 members for agreeing to take part in the interviews.

References

- [1] Stoll C, R. Tenconi R, Clementi M. Detection of Congenital Anomalies by Fetal Ultrasonographic Examination across Europe. *Community Genet.* 2001;4:25-32.
- [2] Garne E, Dolk H, Loane M, Boyd PA, Eurocat. EUROCAT website data on prenatal detection rates of congenital anomalies. *J Med Screen.* 2010;17: 97-98.
- [3] Garne E, Khoshnood B, Loane M, Boyd P, Dolk H, EUROCAT Working Group. Termination of pregnancy for fetal anomaly after 23 weeks of gestation: a European register-based study. *BJOG.* 2010;117: 660-66.
- [4] Mansfield, C, Hopfer S, Marteau TM. Termination rates after prenatal diagnosis of Down syndrome, spina bifida, anencephaly and turner and Klinefelter syndromes: a systematic literature review. *Prenat Diagn.* 1999;19:808-812.
- [5] Garel M, Gosme-Seguret S, Kaminski M, Cuttini M. Ethical decision-making in prenatal diagnosis and termination of pregnancy: a qualitative survey among physicians and midwives. *Prenat Diagn.* 2002;22:881-9-817.
- [6] Registry Prenatal Screening Policies in Europe. 2010;EUROCAT Central Registry. <http://www.eurocatnetwork.eu/prenatalscreeninganddiagnosis/generalinformation/policiesineuropeancountries> (accessed dec, 2017).
- [7] French law no. 45-17 January 17, 2001. <https://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000000700230> (accessed dec, 2017).
- [8] French Public Health Code/Code de la Santé Publique. Art L.2213-1 <https://www.legifrance.gouv.fr/affichCodeArticle.do?cidTexte=LEGITEXT000006072665&idArticle=LEGIARTI000006687544&dateTexte=&categorieLien=cid> ((accessed dec, 2017).
- [9] French Public Health Code/Code de la Santé publique. Art R.2131-10 <https://www.legifrance.gouv.fr/affichCodeArticle.do?cidTexte=LEGITEXT0000060726>

65&idArticle=LEGIARTI000006911250&dateTexte=& categorieLien=cid (accessed dec, 2017).

- [10] French law, Decree June 2015. <https://www.legifrance.gouv.fr/eli/arrete/2015/6/1/AFSP1512973A/jo/texte>
- [11] French Biomedical Agency. Le rapport médical et scientifique de l'Agence de la biomédecine. 2015; <https://www.agence-biomedecine.fr/annexes/bilan2016/donnees/diag-prena/02-centres/synthese.htm#tCPDPN1>
- [12] Dommergues M, Mandelbrot L, Mahieu-Caputo D, Boudjema N, Durand-Zaleski I; ICI Group-Club de médecine foetale. Termination of pregnancy following prenatal diagnosis in France: how severe are the foetal anomalies? *Prenat Diagn.* 2010;30:531-9.
- [13] Ukuhor HO, Hirst J, Clos SJ, William J, Montelpare WJ. A Framework for Describing the Influence of Service Organisation and Delivery on Participation in Fetal Anomaly Screening in England. *J Pregnancy* 2017. vol. 2017, Article ID 4975091, 13 pages.
- [14] Gruchy N, Blondeel E, Le Meur N, Joly-Hélas G. Pregnancy outcomes in prenatally diagnosed 47, XXX and 47, XYY syndromes: a 30-year French, retrospective, multicentre study. *Prenat Diagn.* 2016. 36:523-9.
- [15] Statham H, Solomou W, Green J. Late termination of pregnancy: law, policy and decision making in four English fetal medicine units. *BJOG.* 2006;113:1402-11.
- [16] Hemminki E, Toiviainen H, Santalahti P. Views of Finnish doctors on fetal screening. *BJOG.* 2000;107: 656-62.
- [17] Savulescu J. Is current practice around late termination of pregnancy eugenic and discriminatory? Maternal interests and abortion. *J Med Ethics.* 2001;27:165-171.

- [18] De Vigan C, Vodovar V, Goujard J, Garel M, Vayssière C, Goffinet F. Mothers' knowledge of screening for trisomy 21 in 1999: a survey in Paris maternity units. *Eur J Obstet Gynecol Reprod Biol.* 2002;104:14-20.
- [19] Aksoy S. Antenatal screening and its possible meaning from unborn baby's perspective. *BMC Medical Ethics.* 2001; 2:3.
- [20] Clancy T. A clinical perspective on ethical arguments around prenatal diagnosis and preimplantation genetic diagnosis for later onset inherited cancer predispositions. *Familial Cancer.* 2010;9:9-14.
- [21] French Biomedical Agency/ Agence de la Biomédecine. Recommandations professionnelles de l'agence de la biomédecine pour le fonctionnement des centres pluridisciplinaires de diagnostic prénatal (CPDPN). 2012; https://www.agence-biomedecine.fr/IMG/pdf/recommandations_cpdpn2013.pdf
- [22] Leborne J. L'embryon et le fœtus, entre personne et chose, entre science et droit : des protections d'intérêts : Revue générale du droit on line, 2020, numéro 51180).
- [23] http://www.assemblee-nationale.fr/dyn/15/textes/l15t0474_texte-adopte-seance.pdf
- [24] Lewis C, Silcock C, Chitty LS. Non-invasive prenatal testing for Down's syndrome: pregnant women's views and likely uptake. *Public Health Genomics.* 2013;16:223-32.
- [25] Hill M, Johnson JA, Langlois S, Lee H *et al.*_Preferences for prenatal tests for Down syndrome: an international comparison of the views of pregnant women and health professionalswomen and health professionals. *European Journal of Human Genetics* 2016;24:968-964.
- [26] Metcalfe A, Hippman C, Pastuck M, Johnson JA. Beyond Trisomy 21: Additional Chromosomal Anomalies Detected through Routine Aneuploidy Screening. *J Clin Med* 2014;3:388-415.

- [27] Munthe C. A new ethical landscape of prenatal testing: individualizing choice to serve and promote public health: a radical proposal. *Bioethics* 2015;29:36-45.
- [28] Asplin N, Wessel H, Marions L, Öhman GS. Pregnancy termination due to fetal anomaly: Women's reactions, satisfaction and experiences of care. *Midwifery* 2014;20: 620-27.
- [29] Martin L, Gitsels-van der Wal JT, de Boer MA, Vanstone M, Henneman L. Introduction of non-invasive prenatal testing as a first-tier aneuploidy screening test: A survey among Dutch midwives about their role as counsellors. *Midwifery* 2018;56:1-8.
- [30] Rebouché R. Non-Invasive Testing, Non-Invasive Counseling. *J Law Med Ethics*. 2015;43:228-40.
- [31] Richardson A, Ormond KE. Ethical considerations in prenatal testing: Genomic testing and medical uncertainty. *Semin Fetal Neonatal Med* 2017 Oct 12.
- [32] De Jong A, Maya I, Van Lith JMM. Prenatal screening: current practice, new developments, ethical challenges. *Bioethics* 2015;29:1-8.

Table 1: Foetal indications for medical termination of pregnancy

MALFORMATIONS (WITHOUT CHROMOSOMAL ABNORMALITIES)			123 (46,6%)
BRAIN			40
<i>Anencephaly</i>	16	<i>Septal agenesis</i>	1
<i>Severe degrees of abnormality</i>	5	<i>Holoprosencephaly</i>	1
<i>Agenesis of the corpus callosum</i>	3	<i>Hydrocephalus</i>	1
<i>Hemimegalencephaly</i>	2	<i>Thymic hypoplasia + vermis agenesis</i>	1
<i>Agenesis of the corpus callosum + arachnoidian cysts</i>	2	<i>Arachnoidian cysts + asymmetry of two cerebral hemispheres</i>	1
<i>Craniosynostosis</i>	1	<i>Ventriculomegaly</i>	1
<i>Exencephalia</i>	1	<i>Cerebellar vermis hypoplasia</i>	1
<i>Ischemo-haemorrhagic lesions</i>	3		
POLYMALFORMATIVE SYNDROME			20
RACHIS			20
<i>Spina bifida</i>	17	<i>Severe abnormality (not described)</i>	1
<i>Caudal regression</i>	2		
HEART			16
<i>Complex Heart Disorders (not described)</i>	8	<i>Atrioventricular Communication</i>	1
<i>Tetralogy of Fallot</i>	4	<i>Double inlet left ventricle</i>	1
<i>Aortic atresia</i>	2		
RENAL SYSTEM			13
<i>Megacystis</i>	5	<i>Renal dysplasia</i>	3
<i>Bilateral renal agenesis</i>	4	<i>Severe abnormality (not described)</i>	1
HYGROMA			9
ABDOMEN (DIAPHRAGMATIC HERNIA)			3
MEMBER			2
<i>Femoral Agenesis</i>	1	<i>Hand reduction abnormality</i>	1
CHROMOSOMAL ABNORMALITIES (WITH OR WITHOUT AN ULTRASOUND ANOMALY)			115 (43.6%)
<i>Trisomy 21</i>	65	<i>Trisomy 22</i>	1
<i>Trisomy 18</i>	22	<i>Unbalanced Translocation 18.9</i>	1
<i>Trisomy 13</i>	11	<i>Chromosome 2 deletion</i>	1
<i>Turner</i>	9	<i>Chromosome 4 deletion</i>	1
<i>Triploidy</i>	2	<i>Mosaic (undisclosed)</i>	1
<i>Trisomy 9</i>	1		
GENETIC DISORDERS			13 (5%)
<i>Spinal muscular atrophy</i>	3	<i>Steinert's myotonia</i>	1
<i>Cystic fibrosis</i>	2	<i>Osteogenesis imperfecta</i>	1
<i>Tuberous sclerosis</i>	2	<i>Sickle cell anaemia</i>	1
<i>Achondroplasia</i>	1	<i>DiGeorge syndrome</i>	1
<i>Duchenne muscular dystrophy</i>	1		
INFECTIONS			3 (1.1%)
<i>Cytomegalovirus</i>	1	<i>Rubella</i>	1
<i>Parvovirus B19</i>	1		
OTHERS			10 (3,7%)
<i>Proviably premature rupture of membranes</i>	4	<i>Cord's syndrome</i>	1
<i>Severe Intrauterine growth retardation</i>	3	<i>Foetal immobility syndrome</i>	1
		<i>Anamnios</i>	1
AMOUNT			264

Table 2: Indications present in the medical files according to the number of MCPD presentations

TOP Indications	Case presented	
	one time number (%)	two times or more number (%)
Chromosomal abnormalities	107 (93)	8 (7)
Malformations	75 (61)	48 (39)
Genetic diseases	11 (84,6)	2 (15,4)
Infections	2 (66,7)	1 (33,3)
Others	8 (80)	2 (20)
Amount	203 (76,9)	61 (23,1)
Mean gestational age at TOPFA (wg)	16	24

Table 3: Gestational age at TOPFA according to indications

Indications	Week of Gestation					Amount
	< 13	13-20	21-25	26-29	>32	
Malformations	30	32	32	21	8	123
Chromosomal abnormalities	54	46	11	2	2	115
Genetic diseases	2	4	3	1	3	13
Infections		2		1		3
Others		5	3		2	10
Amount	86	89	49	25	15	264
%	31.7	34.3	18.9	9.4	5.7	100

Table 4: Professional comments from semi-directed interviews

Consensus concerning Down syndrome
“MCPDs don’t work in isolation; they work within society.” (Midwife)
"The organization of screening for Down syndrome in France is a kind of machine for professionals and pregnant women." (Obstetrician)
“The antenatal screening is focused on Down syndrome. When a woman asks for an abortion in this context, her request is accepted. Nothing to discuss!” (Geneticist)
“Actually, there is no question, there is a consensus at the MCPD level.” (Obstetrician)
“We are one of the only countries to be focused on trisomy 21. In England, for example, screening is not organised. There is a greater acceptance of disability.” (Obstetrician)
“Most of the time, women and couples take their decision early, when the exams are prescribed. Their choice is already made at the time of the results. So, the MCPD would not feel legitimate in refusing their request, and this leads to automatic acceptance.” (Midwife)
Situations of uncertainty and notion of particular severity
“So, we have to consider life this child could have after birth.” (Obstetrician, Geneticist)
“After parents have met the different specialists, pediatrician, psychologist and others, at the end we will follow them in their request.” (Obstetrician)
"Couples are very anxious about the uncertainty of the prognosis. In doubt, they don't want to take any risks. Then, -the professionals reach a collegial agreement to terminate pregnancy taking into account the suffering of the couple". (Psychologue)
“In such cases, we can speak of precaution: the "absence of prognosis" makes it impossible to refuse the application request for a termination of pregnancy for medical reason". (Midwife)
About collegiality
“It works well”; “it’s like a firewall” (Midwife, Geneticist, and Obstetrician).
“Each person provides a little of his reality.” (Psychologist).
“You think you are less likely to make a mistake when there are many of you who think the same thing.” (Obstetrician, Midwife).
“The couples understand that they have been heard and understood by a collective and feel more accompanied” (Psychologist).
“The presence of a neutral person, such as a philosopher or ethicist, would be very relevant and might lead prenatal medical professionals to think a little more or differently.” (Midwife)
Time between decision and termination of pregnancy for medical reason / Importance of the medical support
“Couples want to move fast. The concern is to alleviate the anxiety of couples as fast as possible.” (Midwife)
“Consulting the specialist is not a time loss whatever the decision on the outcome of the pregnancy.” (Obstetrician)
"Termination of pregnancy for medical reason is never urgent. However, compassion makes us inclined to go faster to relieve couples." (Obstetrician)
"For chromosomal abnormalities, the discussion does not take place at the MCPD but rather upstream when informing parents of the screening. So, it seems logical to me that the termination of pregnancy for medical reason be carried out as soon as possible after the diagnosis" (Midwife)

"This time is incompressible. I don't know if rushing is good for people? A termination of pregnancy for medical reason is a milestone in a couple's life." (Midwife)