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Frames of decision-making in prenatal consultations in England and France.  
Towards a sociological, relational, and processual approach to autonomy

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1 **Title: Frames of decision-making in prenatal consultations in England and France.**  
2 **Towards a sociological, relational and processual approach to autonomy**

3 **Short running title:** Frames of decision-making in prenatal consultations

4

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25 **Keywords:** Genetic Counselling; Prenatal Diagnosis; Frame analysis; Autonomy; England;  
26 France

27

## 28 **ABSTRACT**

29 Rationale, aims and objectives

30 The article looks at how, during consultations, pregnant women identified as presenting an  
31 increased risk of giving birth to a child with an impairment, and practitioners in the field of  
32 prenatal diagnosis, decide whether or not to accept the risk of a miscarriage and proceed with a  
33 diagnostic examination.

## 34 **Methods**

35 We conducted 63 observations of consultations in France and 22 in England. Participants were  
36 women for whom an elevated risk of abnormality had been identified and the practitioners  
37 involved in their care.

38 Our analytical approach consisted in suspending the normative concepts of non-directiveness  
39 and autonomy, and in drawing on Goffman's (1974) notion of "frame" to take account of the  
40 experiential and structural aspects that the protagonists bring into the (inter)actions.

## 41 **Results**

42 We identified four frames: medico-scientific expertise, medical authority, religious authority  
43 and compassion. Observation of the ways in which the frames intertwine during consultations  
44 revealed configurations that facilitate or hinder the fluidity of the interactions and the decision-  
45 making process. The medico-scientific expertise frame, imposed by the guidelines, heavily  
46 dominated our observations, but frequently caused distress and misunderstanding. Temporary  
47 or sustained use of the compassion and/or medical authority frames could help to repair the

48 discussion and create the conditions that enable women/couples to reach a decision. Variations  
49 in configuration highlighted the differences between practitioners in the two countries.

50 Conclusions

51 Combining frames allows protagonists to exert reflective abilities and to maintain/restore  
52 interactions. The frame analysis promotes a vision of autonomy that is sociological, relational  
53 and processual rather than philosophical. The frames are anchored in different structural  
54 conditions in England and France.

55

## 56 INTRODUCTION

57 Pregnancy-related genetic counselling has developed significantly since the 1970s and the  
58 liberalisation of abortion. Eager to dissociate themselves from eugenic practices, practitioners  
59 placed women's decision-making autonomy at the centre of their work.<sup>1</sup> This orientation is  
60 more broadly embedded in the international context of the rise of bioethics, of women's and  
61 disability movements and of the shift over to the 'therapeutic modernity' model, characterised  
62 by more standardised healthcare practices, regulated away from the doctor-patient relationship  
63 by central bodies that articulate evidence-based medicine with a procedural and "juridicised"  
64 vision of ethics.<sup>2,3</sup>

65 In this context, the concept of autonomy is based on a Western, modern conception of  
66 individuals as rationale beings.<sup>4</sup> It goes hand-in-hand with the principle of "non-directiveness"  
67 that is now an integral part of the prenatal diagnosis (PND) guidelines.<sup>5</sup>

68 In the field of PND, the choice between two risks – that of a child being born with an  
69 impairment, versus that of the loss of a healthy child following amniocentesis – has strongly  
70 influenced the way pregnancy is monitored. The generalisation of antenatal screening and of  
71 increasingly effective imaging techniques now makes it possible to identify "high-risk

72 pregnancies” and detect a large number of anomalies, whilst limiting the loss of healthy  
73 fetuses.

#### 74 *ORGANISATION OF PRACTICES*

75 In countries where abortion is legal, PND is based on a sequence of standardised decisions and  
76 actions. The first decision-action event is Down Syndrome (DS) screening, offered to all  
77 pregnant women in England and France, usually during their first pregnancy consultation.<sup>6</sup>

78 There are nevertheless differences in screening uptake (75% of pregnant women in England,  
79 85% in France).<sup>7,8</sup> Similarly, the threshold at which the risk is deemed sufficient to warrant a  
80 fetal karyotype examination varies (1:150 in England; 1:250 in France). Routine foetal  
81 ultrasound examinations carried out at different points during the pregnancy (two in England  
82 and three in France) enable practitioners to check that the foetus is developing normally and  
83 look for soft markers frequently associated with anomalies.<sup>9</sup>

84 Once identified as being “at increased risk”, women are referred to PND centres located in  
85 public hospitals. Then follows the second decision-action event involving diagnostic tests. This  
86 usually means the extraction of amniotic fluid (amniocentesis) or sampling of trophoblast cells  
87 (Chorionic villus sampling: CVS) with an estimated 1% risk of triggering a miscarriage.<sup>10</sup>  
88 Whilst some abnormalities can be surgically repaired *in utero* or after birth, most of the  
89 anomalies discovered are incurable;<sup>11</sup> the women and couples may then begin a third sequence  
90 of decision-action in relation to a pregnancy termination.

#### 91 *A PRINCIPLE OF AUTONOMY DIFFICULT TO IMPLEMENT*

92 When a risk is identified, practitioners must provide the woman/couple with “information on  
93 the nature of the suspected affection, on the means of detecting it and possibilities for  
94 prevention, treatment, or suitable care for the foetus or child born”.<sup>11,12</sup> The aim is to enable  
95 women to make autonomous decisions and informed reproductive choices. Yet information

96 about Down syndrome is often absent from the consultations.<sup>13</sup> Research on women's decision-  
97 making emphasises the diversity of women's beliefs about ethics,<sup>14</sup> their interpretation of  
98 informed choice,<sup>15</sup> and their attitudes about knowledge sources.<sup>16</sup> Evidence also suggests that  
99 some women view choice as an individual right, while others prefer relying on practitioners'  
100 advice.<sup>17,18</sup> Other studies indicate that it is often difficult for practitioners to comply with  
101 neutrality and non-directiveness.<sup>19</sup>

102 Practitioners admit to being directive in certain situations,<sup>17,20</sup> as they make assumptions on  
103 women's scientific and linguistic skills, their religious beliefs, and knowledge of abortion  
104 legislation.<sup>21,22</sup> Direct observations of counselling practices demonstrate the complexity of  
105 women and practitioners' interactions, which is largely caused by differing interpretations of  
106 the concept of risk.<sup>23</sup> Schwennesen and Koch observed that the act of « doing good care », by  
107 minimising emotional suffering and supporting a pregnant woman's ability to make meaningful  
108 choices, is difficult to reconcile with the ideal of non-directiveness.<sup>24</sup>

109 The difficulty to adopt the recommended non-directive approach poses important questions. On  
110 one hand, it might reveal the persistence of a form of paternalism in the relationship between  
111 women and practitioners, with the latter possibly struggling to accept women's autonomy in  
112 decision-making. On the other hand, it might reflect a conception of autonomy that is too  
113 restrictive to take account of the relational dynamics taking place in clinical consultations. To  
114 address these questions, it is essential to examine what the interactions between women and  
115 practitioners consist of by suspending, during the analytical process, any normative reference  
116 to autonomy and non-directiveness.

117

118 In this article, we focus on the second sequence of decision-action in PND pathways, where  
119 women identified as being "at risk" are sent to referral centres where they must decide whether  
120 to continue with the investigations or not.

121 In line with pragmatic sociology, using Frame Analysis,<sup>25</sup> we first describe and categorise the  
122 interactions that take place during the consultations, the way women and practitioners engage  
123 and adjust to these interactions, as well as the conditions that facilitate or hinder the  
124 protagonists' expression of their reflective capacities. This then lead us to consider and  
125 challenge the philosophical conception of autonomy, and propose, instead, a sociological  
126 conception of autonomy that is both relational and processual, and which we discuss in relation  
127 to the organisation of PND practices in England and France.

128

## 129 **METHODS AND MATERIALS**

130 Our analysis is based on observations of PND consultations to which women are referred when  
131 there is an increased risk of foetal anomaly. Sixty-three observations were conducted in France  
132 between 2010 and 2012 in a PND referral centre in the Paris region, which receives a high  
133 proportion of immigrant women, most of them from North Africa, and in a provincial centre  
134 which treats a mixed population. Twenty-two observations, involving a mixed population, were  
135 conducted in England in 2013, in a gynaecological and obstetric unit in a hospital that practices  
136 foetal medicine and in a foetal medicine unit in a referral centre. In our observations, the  
137 increased risk resulted from DS screening (39), ultrasound imagery (24), genetic/obstetric  
138 history (12), maternal age (8) and toxoplasma infections (2).

139 We must begin by pointing out a difference between the two countries in terms of health  
140 pathways. In England, women are informed of their risk and only sent to a referral centre if they  
141 consider that taking a sample is an option. A midwife then goes over the information on the  
142 risks before obtaining the woman's consent. An ultrasound examination is then performed; the  
143 consultant answers any questions the women may have and the sample is taken. In France, all  
144 women "at risk" are referred to a PND centre. Approximately one third of the consultations

145 follow the same format as those in England. The remainder are conducted by a midwife alone,  
146 who provides information. No medical act is performed.

147 The study received ethical approval in France from a Research ethics committee (Anonymised)  
148 and in England from the Health Research Authority (anonymised) and the University of  
149 (Anonymised) ethics committee. Consultations lasted between 25 and 70 minutes. 40 women  
150 attended the consultations on their own, 42 were accompanied by their partners and three by  
151 someone else. The authors were present during the consultations. Field notes were made to  
152 capture the communication's content and delivery as well as non-verbal expressions. In  
153 England, the consultations were also recorded and transcribed verbatim.

154

155 The analysis, conducted by both authors, draws on Grounded Theory.<sup>26</sup> It focuses on the nature  
156 and properties of the (inter)actions taking place during the consultations and how these are  
157 combined to enable a decision regarding the management of the pregnancy to be reached. These  
158 interactions are heterogeneous and relate to medical practices, their organisation and regulation.  
159 Yet most of these actions are “speech acts”,<sup>27</sup> i.e. discourses which inform, reassure or worry,  
160 protect, advise, influence, etc.

161 Based on frame analysis,<sup>25</sup> the first analytical stage consisted of identifying the different frames  
162 mobilised by protagonists during the consultations. The frames act as guides to action, they  
163 convey ordinary meanings of what takes place in a situation and of the ways people behave  
164 therein. The second analytical stage, which draws on “combinatory pragmatics”,<sup>28</sup> consisted of  
165 identifying from the combination of frames and their impact on the interactions, the different  
166 configurations of consultations and their outcome in terms of decision-making.

167

168 **RESULTS**

169

170 *FRAMES OF DECISION-MAKING AT WORK IN PND CONSULTATIONS*

171 We identified four frames from the interactions we observed. Three of these carry the rational  
172 resources that might guide the decision-making: the frames of medico-scientific expertise,  
173 medical authority and religious authority. A fourth frame offers resources that can mitigate the  
174 emotional charge and thus supports the interactions; we call it the compassion frame.

175

176 **The medico-scientific expertise frame**

177 This frame was predominant in our observations, articulating a moral stance that supports the  
178 actors' ability to make rational and autonomous choices<sup>3,4</sup> with a grid for understanding  
179 situations based on the medico-scientific rationale at work in evidence-based medicine. This is  
180 the frame that dominates the 'therapeutic modernity'.<sup>2</sup> Practitioners are tasked with helping  
181 women decide whether to continue with the investigations, and therefore accept the risk of  
182 miscarriage when a sample is taken. This presupposes that women have acquired sufficient  
183 expertise regarding the model for calculating risks and interpreting their significance, and that  
184 practitioners have provided clear information without engaging their own subjectivity. The  
185 actions taking place within this frame thus essentially involve providing/receiving/asking for  
186 scientific and technical information relating to the nature of the risks, their value and mode of  
187 calculation, how the medical acts are performed, and the aetiology and consequences of the  
188 suspected pathologies.

189 All the consultations we observed began in the medico-scientific expertise frame with the  
190 practitioner explaining the risk as being the reason for the consultation. *"I'm seeing you today  
191 to discuss the results of the blood test. It allows us to evaluate the statistical risk of having a*

192 *child with Down Syndrome. Your risk is...*” (Midwife, France). Detailed technical information  
193 is then provided, depending on the type of risk.

194 *“It would appear that you have contracted a toxoplasmosis. [...] The risk of transmission*  
195 *increases with the term. At the beginning of the pregnancy it is 1%, at 9 months it is 80% of*  
196 *babies who are contaminated. [but]the consequences are not the same. If it is before 15 weeks,*  
197 *there can be serious consequences. Toxoplasmosis attacks the entire organism but the most*  
198 *serious consequences are on the brain”* (Consultant, France).

199 Once the information on possible foetal anomalies has been given, the practitioner provides  
200 details on the risk of miscarriage when a sample is taken. The risk is frequently weighted by  
201 information on the expertise of the operator, designed to reassure:

202 *“The risk here is lower than the national average and the reason for that is because we do these*  
203 *tests every day... and of course the consultants that do these tests do them all the time, so they*  
204 *are experienced. So your risk of miscarriage as you enter the room is less”* (Midwife, England).

205 In England, practitioners also explain another risk, that of the culture of amniotic cells not  
206 giving any meaningful result or ending in a ‘laboratory failure’, estimated at less than 1%.

207 Given the technical nature of the information, the medico-scientific expertise frame is a  
208 demanding one as it requires the appropriation of complex knowledge. Therefore, practitioners  
209 often employ sophisticated strategies such as the lottery metaphor, frequently used in the  
210 consultations observed in the Parisian centre: *“Your risk is 1:197. It’s as if your uterus was the*  
211 *lottery chamber, there are 196 white balls and one red; but we don’t know which one is in your*  
212 *tummy”* (Midwife, France).

213

214 **The medical authority frame**

215 As a persistent form of doctor-patient relationship rooted in the “clinical tradition”, in the  
216 medical authority frame and by virtue of their experience, clinicians can legitimately express  
217 opinions, give advice and orient the decisions of their patients.<sup>2</sup> This frame is difficult to  
218 reconcile with that of the medico-scientific expertise, which established itself as the opposite  
219 of the medical authority paradigm. It is, therefore, only brought into play when the course of  
220 (inter)actions requires some adjustment. The analysis of our observations reveals three reasons  
221 for turning to medical authority.

### 222 *Medical authority to repair the exchanges*

223 A situation may occur where the practitioner suddenly realises that the information he/she has  
224 just given, is upsetting the woman and/or her partner. It is often when he/she is coming to the  
225 end of his/her expert explanations by asking if there are any questions, that the woman expresses  
226 her concerns. At this stage, some practitioners use the medical authority frame as a way of  
227 “repairing” the emotional harm that the medico-scientific discourse has caused. This might  
228 mean a brief incursion during which the practitioner sets aside the neutral attitude and adopts  
229 that of the benevolent authority of someone who has the answers and can be trusted. At the very  
230 least, this comes in the form of a comment that qualifies the information that have just been  
231 given: “*You know the information now, don’t think about that anymore [...] we are very, very*  
232 *positive here in terms of the situation. I mean it sounds very good.*” (Midwife, England)

233 The practitioner will occasionally engage his/her subjectivity before picking up the threads of  
234 the medico-scientific arguments. In the Parisian unit, repair sometimes goes hand-in-hand with  
235 a justification that the practitioner uses to free him/herself from the recommended principle of  
236 neutrality, so as to better adjust to the woman’s distress: “*You are 30 years old. The neck is*  
237 *thin. I’m not worried but we have to have this conversation [...] I have to give you the most*  
238 *reliable information possible*” (Midwife, France).

239

240 *Medical authority requested by women: delegating the decision*

241 Women may turn to the medical authority frame by explicitly asking for the practitioner's  
242 opinion. More often than not, the practitioner will maintain a neutral stance: "*I'm not the one*  
243 *who will be holding this baby in my arms. It would be dishonest of me to say 'in your position*  
244 *I would do it''*", (Midwife, France), which sometimes causes tension in the discussion as seen  
245 from this consultation in England:

246 *Woman: What do you think we should do?*

247 *Consultant: I can't tell you.*

248 *Woman: Of course you can!*

249 *Consultant: Our personalities are not the same.*

250 *Woman: You should still tell us.*

251 *Consultant: Doctors can't tell you what to do in these circumstances.*

252 *Woman: I think you should.*

253 The neutral attitude can sometimes be interpreted as the practitioner's disengagement from the  
254 clinical relationship, thus causing the women to feel abandoned.<sup>29</sup>

255 More rarely, practitioners will accept delegation of the decision following an explicit request  
256 from women who do not wish to engage in an expert approach and who wish to leave it up to  
257 professionals. The asymmetry is chosen and accepted with due regard for the protagonists. In  
258 France for example, with a certain amount of assurance, a woman of African origin interrupts  
259 the obstetrician's explanations by saying: "*Doctor, it's you who decides, because we don't know*  
260 *anything about all this!*" The request is understood and the practitioner accepts the delegation.  
261 He questions the couple on several occasions so as to adapt his advice to suit their expectations,  
262 understands that for religious reasons abortion is not an option, and to the satisfaction of the

263 couple, concludes: *“In my opinion no sample should be taken. You say I am the doctor and that*  
264 *I must advise you. That is my advice.”* (Consultant, France).

265

266 Although certain English practitioners sometimes accept to give an opinion, this does not mean  
267 that the neutrality and objectiveness, characteristic of the medico-scientific expertise, are set  
268 aside. Each opinion is accompanied by a technical argument to such an extent that the frames  
269 of expertise and medical authority are very much entwined.

270 For example, during the ultrasound examination preceding a planned CVS, and when the  
271 development of the foetus seems to be normal, the woman is submerged by doubt:

272 *Woman: So, do you think we should still go for the CVS?*

273 After explaining the advantages and limitations of imaging and karyotyping, the consultant  
274 concludes: *“It’s true that the scan is not 100% reliable, okay? So it’s two complementary*  
275 *things”*.

276 *Woman: So because the nuchal scan was 2.8mm, that’s why we want to go ahead and get this*  
277 *done.*

278 *Consultant: It is your choice.*

279 *Woman: But you think that’s good still to do?*

280 *Consultant: Yes! If you want to have peace of mind, this is not unreasonable.*

281 *Woman: And the chance of miscarriage is so small that you think...*

282 *Consultant: It’s slightly less than 1 in 100*

283 *Woman: So it’s worth it...*

284 *Consultant: Yes why not!*

285

286 *Imposed medical authority: orienting the decision*

287 In some cases, medical authority is imposed without being requested by the woman/couple.  
288 This is often the case in France when women are hesitating to have a sample taken. They are  
289 often dissuaded from doing so if they are determined to keep the child they are carrying. For  
290 example, the midwife explained to a couple carrying the drepanocytosis gene: “*We can make*  
291 *the diagnosis before birth, but we need to ask what we’re going to do. If [the foetus] is affected,*  
292 *are we going to terminate the pregnancy?*” Following the woman’s negative response, she  
293 continued: “*the only thing we can do is an amniocentesis. But there’s a risk of miscarriage.*  
294 *That’s why, if you wish to keep this child, it’s better not to do [the amniocentesis]*” (Midwife,  
295 France).

296 Finally, the practitioner’s attitude can be clearly directive when there is a strong presumption  
297 of anomaly. In France, for example, the consultant immediately told a 45-year-old woman: “*As*  
298 *you have unfavourable blood results, with a very high level of hormones, this suggests a risk of*  
299 *chromosomal anomaly. It would be a good idea to rapidly have an amniocentesis to reassure*  
300 *you.*” When facing what is considered to be a high risk, there is pressure to move fast.

301

### 302 **The religious authority frame**

303 The religious authority frame is sometimes mobilised during consultations. For some women,  
304 the underlying world order cannot be reconciled with the possibility of losing a foetus due to a  
305 sample being taken, and even less with a termination of pregnancy. Procreation is seen as a gift  
306 from God; neither women nor doctors have the right to change the course of the pregnancy.

307 In rare cases, couples explicitly refer to the religious authority frame when the practitioner has  
308 finished speaking. “*Stop all the tests. I take full responsibility. Inshallah [...] I want this baby,*

309 *Down Syndrome or not, no problem. It's fate.*" (African partner, France). In other cases, it is  
310 the practitioners themselves who mobilise this frame, to explore the woman's opinion  
311 concerning the possibility of terminating the pregnancy. In the Paris centre, this strategy is  
312 frequently employed on women, who are assumed to be Muslims. Having delivered the  
313 standard information on the risk of DS and of miscarriage associated with taking a sample, the  
314 midwife asks the woman:

315 *Midwife: "You must tell me if you want us to do this test".*

316 *Woman "No".*

317 *Midwife: "Why don't you want it?"*

318 *Woman: "If there were no risk, I'd do it. In our country it's not a good thing, because God will  
319 punish us".*

320 *Midwife: "If you knew for certain that the child had Down Syndrome, what would you do? We  
321 terminate the pregnancy or we continue?"*

322 *Woman: "I can't terminate"*

323 The midwife wants to be certain that the woman's choice is truly rooted in religious authority  
324 and not in a "false belief" concerning the risk of a miscarriage. The woman's confirmation  
325 generally puts an end to the interactions. Such situations often lead to reciprocal mistrust. This  
326 can be seen in the post-consultation comment made by a French consultant concerning a woman  
327 whose foetus is at risk of a genetic disease and who, for religious reasons, twice rejected the  
328 offer of a diagnostic test: "*It's not complicated. For us she just wouldn't listen!*". The few times  
329 the woman spoke during the ultrasound examination shows how little she believed in  
330 technology. When the obstetrician observes that "*the baby is not very big, especially the head*",  
331 she retorts: "*my first child also had a small head, but afterwards it grew*" (African woman,

332 France). Women's mistrust of medicine can also be found in England: "*the doctor told me that*  
333 *a baby would have disability but when the baby is born ...it was a minor problem*"

334 The religious authority frame may remain latent in many situations; women turn to this frame  
335 to make a decision, without necessarily offering any justification, either because they feel it is  
336 a private matter, or because they fear a negative reaction or insistence from practitioners.

337

### 338 **The compassion frame**

339 Compassion offers no cognitive resources with which to make a decision; it is used to calm the  
340 anxiety which often increases as information is provided, and thus supports, or even re-  
341 establishes, interactions. Compassion supposes that distress is recognised. It may be used in  
342 conjunction with the medico-scientific expertise frame to demonstrate empathy and  
343 benevolence, or when the practitioner becomes aware of the anxiety that the information has  
344 caused. Resources are numerous and heterogeneous; therefore, the compassion frame can be  
345 easily intertwined with other frames. It can be confined to demonstrations of neutral concern,  
346 such as the use of softly spoken verbal phrases ("it's alright my darling", "don't worry about  
347 it"), or to gentle and kind-hearted gestures, such as passing a box of tissues to a woman who is  
348 crying, placing a hand on her arm, or using humour. The practitioner might signal his/her  
349 availability by suggesting another appointment or a telephone call: "*if you are still worried*  
350 *when you get home, give me a ring*" (Midwife, France). In certain cases, practitioners may  
351 suggest postponing the decision to a later date or term. Finally, the compassion frame can also  
352 be used in conjunction with that of medical authority, when the practitioner engages his/her  
353 subjectivity in the assessment of a test result: "*in your case the risk is very, very low*".

354

### 355 **COMBINING FRAMES**

356 The second analytical stage consisted of examining how the protagonists combine the different  
357 frames taking account of the eventual ruptures and adjustments that occur in the short time that  
358 consultations last, and their impact upon the nature and degree of fluidity of the interactions.<sup>30</sup>  
359 This systematic approach revealed a range of consultation configurations. We will focus on the  
360 three most frequent ones.

361

### 362 **When protagonists mobilise the same frame**

363 In several cases, the medico-scientific expertise frame is common to both practitioners and  
364 women – the latter are often already informed but require additional information to make or  
365 confirm their decision. The protagonists thus engage in continuous and fluid interactions, the  
366 scientific and technical content of which is rooted in evidence-based medicine.

367 In the following extract, a couple has been referred to the French provincial centre for a risk of  
368 DS of 1:130. The woman wants more information about the risk of miscarriage, which the  
369 midwife estimated to be 1:200. The woman initiates the dialogue and concludes with her  
370 decision to have the amniocentesis:

371 *Woman: “It is very important to me to understand what you are telling me. If we don’t*  
372 *understand, the decision is not very informed”.*

373 The midwife writes her calculation on a piece of paper.  $X=100/130$ . The woman uses her  
374 calculator: *“That gives 0.77. There is a 0.77 chance out of 100 that there is a problem [with the*  
375 *foetus]”.*

376 *Midwife: “Tell yourself it’s a little less than 1%”.*

377 *Woman: “I have less chance of losing the child because of a miscarriage, than of there being*  
378 *a problem”.*

379 Three conditions favour fluid and continuous interactions in the medico-scientific expertise  
380 frame. Firstly, women must be engaged in this frame, of which they have some understanding,  
381 and be ready to receive or ask for scientific and technical information to make or confirm their  
382 decision. Secondly, it must be possible to contain the emotions that are generally aroused when  
383 talking about the risks of pregnancy. These two conditions are more easily met when women  
384 have been informed of their risk prior to the consultation and have already begun to think about  
385 it. Thirdly, there must be an opportunity for women to interact with practitioners. This means  
386 that either women feel it is legitimate to spontaneously interact or that practitioners encourage  
387 them to do so.

388

### 389 **When protagonists mobilise frames difficult to concile**

390 It is not rare for protagonists to approach a consultation using different frames. Such situations  
391 tend to rigidify interactions and sometimes lead to distortions likely to hinder the decision-  
392 making process.

393 When engaged in the medical authority frame, women do not expect a general explanation of  
394 pregnancy risks but the practitioner's opinion of their personal situation. Above all, they seek  
395 reassurance and/or guidance. The medico-scientific expertise frame, which orients the  
396 practitioner's attitude, and the medical authority frame which directs that of the women, thus  
397 enter into opposition. Waiting for an opinion on her personal situation that does not come, the  
398 woman may start to think that the technical information she is receiving is a prelude to the  
399 announcement of bad news. The length of time it takes to provide this information increases  
400 her distress further. In France, after quietly listening to the midwife explain the way DS  
401 screening works, receiving information on the pathology, with photos of children with the  
402 syndrome, a woman, of African origin, begins to cry and her partner, who can no longer keep  
403 quiet, interrupts the midwife: "*Excuse me, but does this concern us?*".

404 The tension caused by the confrontation between the two frames generally leads to a high  
405 emotional charge that hinders the fluidity of the interactions. It can nevertheless be reduced by  
406 exposing the gap between the woman's expectations and the demands of the medico-scientific  
407 expertise frame. This is what the midwife attempts to do when she begins her consultation with  
408 a preamble destined to reassure the couple: "*The first thing we need to be clear on is that baby*  
409 *might be absolutely normal, OK? This is a risk assessment*" (Midwife, England). However, the  
410 concept of risk is not always well understood and the preamble not always enough to contain  
411 emotions. These situations have different outcomes. The decision might be postponed and a  
412 new appointment made, as is often the case in France. The woman might also choose to have  
413 the sample taken as a way of resolving the distress caused by the expert discourse.

414 The women/couples who approach pregnancy and its monitoring through the frame of religious  
415 authority do not begin consultations with the intention of gathering information that will help  
416 them to make a decision. Their decision has already been made. Yet they are rarely given the  
417 opportunity to express their position from the outset and some women feel that they do not have  
418 the legitimacy to interrupt the practitioner and assert their point of view. As for the practitioner,  
419 providing neutral, objective scientific and technical information is a regulatory duty.  
420 Practitioners must obtain signed consent from women before taking a sample. As they do not  
421 know how their colleagues informed the patient, or how the information had been understood,  
422 they repeat the entire content. When the opinion is based on medico-scientific expertise, there  
423 is no major problem. However, when the decision (not to have a sample taken) has been made  
424 in the religious authority frame, the situation is very different. The practitioner's pursuit of  
425 his/her role to inform can be interpreted as a lack of respect, as the invalidation of the couple's  
426 point of view, a way of asserting that only medico-scientific expertise can legitimately form the  
427 basis for a decision. Again, the length of time taken to provide the information tends to increase  
428 the emotional charge which then translates into mistrust and resentment, and which can lead to

429 an obstinate silence or, sometimes, definitive remarks: *“Doctors don’t know anything; only*  
430 *God knows”* (France). This consultation configuration does not provide the conditions required  
431 for fluid interactions. The tension can sometimes be resolved when the content of the  
432 interactions shifts towards the routine monitoring of the pregnancy. It can reach a peak when  
433 the practitioner looks to protect him/herself from any legal action by noting in the medical file  
434 that the woman, after receiving all of the required information, refuses to undergo a diagnostic  
435 examination.

### 436 **When protagonists adjust frames to restore fluid and continuous interactions**

437 In situations where dialogue is blocked or where the emotional charge is high, temporarily or  
438 definitively abandoning the frame of medico-scientific expertise can sometimes be, for  
439 practitioners, the only way of restoring interaction. A shift into the repertoire of medical  
440 authority or compassion, repeated as many times as is necessary, can revitalise interactions.

441 So when explanations relating to DS are interrupted by the partner of a woman, who asks  
442 *“Excuse me, but does this concern us?”*, the midwife realises that the information has not been  
443 understood. She therefore momentarily ceases to impart knowledge to the couple, and brings  
444 her subjectivity into play to reassure them: *“You are 30 years old, I’m not worried, but I have*  
445 *to talk to you like this; it’s so that I can explain”*. The incursion into the reassuring medical  
446 authority frame enables the midwife to return to that of medico-expertise. The interactions  
447 continue, the midwife pays attention to the couple’s needs and mobilises resources to support  
448 her actions:

449 Midwife: *“Amniocentesis is the only way to be sure”*.

450 Partner: *“As you said, there’s a risk, so it’s better not to do that”*.

451 Midwife: *“It all depends on what is important for you. If this pregnancy is very important and*  
452 *you don’t want to risk a miscarriage, then I say ‘fine’. If you tell me that you don’t want a child*  
453 *with Down Syndrome, then I also say ‘fine’”.*

454 Partner: *“It’s her decision”.*

455 Midwife: *“We can take our time. We can meet again in a few days so that I can explain again.*

456 Woman: *“I prefer to think about it. [...] What if we redo the ultrasound to look again at the*  
457 *neck?”*

458 Midwife: *We only do that at the start of the pregnancy”.*

459 The decision is deferred, the midwife notes down the information she has given to the woman  
460 and a new appointment is made.

461 The temporary abandon of the medico-scientific expertise frame and the incursion into that of  
462 medical authority for reasons of solicitude allowed to restore the course of interactions. In  
463 France, many consultations demonstrated this type of adjustment.

464 More rarely, the practitioner’s recourse to the medical authority frame causes a turning point in  
465 the course of the consultation. In France, a woman of Muslim faith consults the geneticist who  
466 had monitored her when the child she had given birth to one year ago died of a genetic disease  
467 only a few days old. Pregnant again, she is terrified that it might happen again:

468 *Woman: I don’t know what to do. I’m lost.*

469 *Consultant: Let me simplify. There are two attitudes, both of which are acceptable. It’s up to*  
470 *you to decide which is the best for you.*

471 *Woman: That’s what’s difficult. I can’t make a decision.*

472 *Consultant: Let me summarise. If we don’t do anything [...] three times out of four everything*  
473 *will be fine. One time out of four the child will have the same disease as [first child] and*

474 *unfortunately there'll be nothing we can do. It will die during the first few days of its life. Second*  
475 *solution, we perform a biopsy at 12 weeks. We'll have the results one week later. Three times*  
476 *out of four there'll be nothing, and you can relax. [...]*

477 *Woman: In fact I'm scared of taking the risk of losing a child who is not ill.*

478 *Consultant: Unfortunately, that can happen. [...]*"

479 *Woman: What is the risk of me miscarrying?*

480 *Woman: No, I'd never get over it!" [...]* *What do you think I should do?*

481 *Consultant: I fear that you're never going to be able to relax during this pregnancy [...]*  
482 *exceptionally, I'm going to allow myself to give you my opinion. It's up to you to make the*  
483 *decision. It's maybe worth taking the 1% risk. Even though you don't know what you'll do*  
484 *afterwards".*

485 The change of frame gives the woman the opportunity to mention her partner's refusal to have  
486 a sample taken, a refusal rooted in the religious authority frame. She fears a possible  
487 miscarriage, for which she would be blamed. The geneticist, adapting to the situation, offers to  
488 take some of the responsibility by producing a letter addressed to the partner, and that he vocally  
489 records in the woman's presence: "*we believe that the benefit you will get from knowing the*  
490 *status of your child, healthy or ill, is a real one, because it will allow you to project yourselves*  
491 *into this pregnancy. Something that you are having trouble doing."*

492 This form of benevolent directiveness shows the woman that her distress and needs have been  
493 taken seriously. By looking together at the available possibilities, the woman and the  
494 practitioner engage in pragmatic reflexivity and create the conditions for reaching a decision  
495 together.

496

## 497 **DISCUSSION**

498 Over the past three decades, genetic counselling has undergone many transformations,  
499 increasing regulation and standardisation of PND consultations. Although the objective is to  
500 take better account of women's viewpoints in a decision-making process, these changes give  
501 PND consultations a particularly restrictive framework. The obligation placed upon  
502 practitioners to inform women, in an objective, neutral and accessible way, of the two types of  
503 risk that they are facing (that of having a disabled child and that of having a miscarriage) tends  
504 to make interactions more rigid. Our observations confirm the obstacles that stand in the way  
505 of this objective. They demonstrate the distress women experience when having to make a  
506 decision that affects the life of the child they carry,<sup>31</sup> and the difficulty for practitioners to  
507 maintain neutrality in light of the heterogeneity of women's backgrounds, their beliefs, level of  
508 understanding as well as social and ethnic origins.<sup>21</sup> Our study suggests that in most situations  
509 the stated objective of neutrality is unachievable. However, one might also question what the  
510 objective of these consultations actually is. If the objective is to guarantee women's and  
511 couple's freedom of choice, our analysis suggests several ways to achieve it. Reaching a  
512 decision on whether or not to have a sample taken, after understanding everything that is at  
513 stake, is just one of several modalities for achieving this objective. Furthermore, as we have  
514 seen, this modality supposes that the protagonists engage in a common frame, that of the  
515 medico-scientific expertise, that emotions do not run too high and that women feel that they  
516 can legitimately interact with the practitioners. Yet these conditions are far from being  
517 systematically met.

518 The first lesson learned from our analysis is that the protagonists can participate in the  
519 consultation by navigating between different frames, which can lead to communication  
520 problems and distortions. For the practitioner engaged in the medico-expertise frame, the act of  
521 informing in a neutral and objective manner is the condition for respecting the woman's

522 autonomy, whereas for the woman engaged in the medical authority frame, it can be a sign of  
523 imminent bad news. Designed to help the woman make her decision, information instead causes  
524 distress and hinders her reflective capacities. Similarly, whilst for the practitioner the act of  
525 informing is a prerequisite of consent, for the woman engaged in the religious authority frame,  
526 it can be interpreted as the negation of her opinion – an opinion she is not even asked to give.  
527 Once brought to light, it should be possible to find practical solutions for these distortions.

528 The second lesson learned from our analysis is that the emergence of a decision does not come  
529 about in a unique action frame that should be preferred. On the contrary, we were able to  
530 identify different configurations resulting from distinct arrangements of the frames used during  
531 consultations. This might mean repeated incursions into the compassion and/or medical  
532 authority frames to contain emotion, to then return to the medico-scientific expertise frame; or  
533 an assumed distancing from the role of expert; or a voluntary and assumed delegation to medical  
534 authority. In other words, despite the considerable constraint that practice regulations impose  
535 upon the coordination of actions, in certain situations the protagonists manage to restore fluid  
536 and continuous interaction, adapted to their expectations and values and orienting them towards  
537 a decision.<sup>4</sup> This observation clearly demonstrates the limited relevance of abstract notions such  
538 as neutrality and non-directiveness when it comes to qualifying and taking account of the work  
539 done by protagonists during consultations. The various configurations of consultations  
540 identified in our analysis indicate that, on the contrary, practitioners' relational involvement,  
541 and even in some cases practitioners' directiveness, might be necessary to maintain/ restore  
542 interaction and enable women and couples to exert their reflective capacities.

543 Aiming for women's autonomy as conceptualised in the philosophical tradition as rational  
544 individuals' capacity for self-determination, may therefore not be appropriate to 'real-life  
545 situations' of PND consultations. Indeed, women's enfranchisement from material and social  
546 considerations that underpins this definition was seldom observed in our consultations. Instead,

547 a sociological concept of autonomy based on a relational process involving all protagonists and  
548 enabling a mutual adjustment of actions might be better suited to generating a reflective  
549 approach to practice. From that perspective, respecting women's and couples' autonomy would  
550 be less about maintaining a neutral and non-directive attitude, and more about facilitating the  
551 expression of their reflective capacities.

552

553 The frame analysis provides insights into the constraints that govern interactions. The way  
554 protagonists define the situation as well as their expectations reflect past experiences, which  
555 are themselves anchored in social structures and practices. For example, the medico-expertise  
556 frame is rooted in the 'therapeutic modernity' era: PND practitioners have acquired a specific  
557 conception of their mission and have developed routines for their consultations – based on their  
558 training, their experience, and on a certain number of rules – and have learned to adapt them to  
559 suit individual situations. By contrast, the medical authority frame is rooted in the “clinical  
560 tradition”.<sup>2</sup> Women who engage in that frame tend to defer to its representative and expect to  
561 be reassured, or at least advised on their particular situation. “People therefore must manage  
562 the plurality of frames, as well as the eventual ruptures of frames that rise in the course of  
563 interactions”.<sup>30</sup> Being cognisant of this plurality might encourage practitioners to consider  
564 women's viewpoints, and thus promote interactions. It might also result in making the medico-  
565 expertise frame intelligible to women, for example, by making it clear that the information they  
566 are about to receive is not specific to their situation but is given to all women, and is designed  
567 to “train” them in scientific reasoning to help them make a decision.

568

569 It would seem hazardous to compare PND practices in England and France on the basis of our  
570 data due to the small number of observations and the diversity of the populations. Moreover,  
571 the way pregnancy monitoring is organised is different. It appears to be more delineated in

572 England, thus making it possible to limit the number of acts and, therefore, better control  
573 spending. This can also be seen in the legal framework governing practices, with regard to the  
574 thresholds at which samples may be taken (higher in England) and in the lower number of  
575 ultrasound examinations that are recommended. This observation is reminiscent of public fund  
576 management practices found in England since the 1980s and the way in which the new rules  
577 and procedures introduced by the State have durably guided the behaviour of health actors.<sup>32</sup> In  
578 France, pregnancy monitoring is more flexible, and although PND practices have been  
579 subjected to greater regulation since the 1990s, practitioners retain relative autonomy.<sup>33</sup>

580 As we observed, in England these differences lead to the virtual absence of recourse to the  
581 religious authority frame, because women who are engaged in this frame and refuse to take the  
582 risk of miscarriage, generally do not move on to the second decision-action sequence that  
583 constitutes the subject of this study. By the same reasoning, due to this filtering of the care  
584 pathway, women who are not opposed to a sample being taken tend to be better informed about  
585 their situation and more familiar with the medico-scientific logic than the women observed in  
586 France.

587 Yet more subtle differences can also be observed. English practitioners seem to more frequently  
588 adopt attitudes of neutrality and non-directiveness and demonstrate a stronger attachment to the  
589 medico-scientific expertise frame, whereas French practitioners do not hesitate to distance  
590 themselves from it. English practitioners also appear to be more involved in the mission to  
591 educate women – something that is especially evident in the level of detail in the information  
592 provided that is greater than in consultations in France. Here we find the expression of a form  
593 of incorporation of the tools that regulate practices and provide guidelines.<sup>32</sup> This avenue of  
594 interpretation nevertheless needs to be verified in a later study, as these differences might also  
595 be attributed to practitioners adapting to women's individual characteristics and might reflect  
596 the work culture in operation in the establishments in which we conducted our observations.

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601

602 **Conflict of interest**

603 The authors have no conflict of interest to declare.

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