

**THE HOUSE OF LORDS SELECT COMMITTEE ON SCIENCE AND
TECHNOLOGY**

INQUIRY INTO GENOMIC MEDICINE

**EVIDENCE SUBMITTED ON ‘POLICY FRAMEWORK’: IN WHAT WAY IS
SCIENCE AND CLINICAL POLICY DECISION-MAKING INFORMED BY
SOCIAL, ETHICAL AND LEGAL CONSIDERATIONS?**

Summary

This paper addresses one of the five questions in the section on ‘Policy Framework’. It will argue that greater regulation may be needed of clinical decisions to offer carrier testing to children (including adolescents). Although guidelines for carrier testing were established in 1994, the interpretation of these guidelines appears to be flexible in practice. Evidence from research¹ undertaken as part of the programme of work of the ESRC Centre for the Economic and Social Aspects of Genomics (Cesagen)² suggests that early testing may not be in the best interests of these young people and that they may not fully understand the implications of being tested at a stage in the life-course where the results are not immediately relevant to them. We also draw upon our observation of a meeting held on 6 July, 2007: ‘Genetic Testing of Children: How should we decide?’,³ at which it was clear that UK medical practitioners are inclined to meet parental requests for testing before their children have reached the age of majority, despite the existence of self-imposed clinical guidelines. The application of the notion of Gillick-competence may not be appropriate to carrier testing and it may be that the self-regulation of the medical profession needs to be curtailed by the development of government policy in this area.

1. Introduction: Professions and Regulation

1.1 In his recent book, Mark Davies makes the following observations about the regulation of professions, and in particular, the medical profession:

“Professions such as medicine involve the provision of services which are of high importance to clients and require high levels of expertise and judgement by the professional. The client is frequently unable to accurately assess [sic] the quality of service. External models of regulation, it is often argued, are unsuited

¹ ‘The Transgenerational Communication of Genetic Information’, funded (2004-7) by The Wellcome Trust, undertaken as part of the programme of work of Cesagen. The principal investigators were Professor Angus Clarke and Professor Paul Atkinson.

² This evidence is submitted separately from that by Cesagen (which is subsumed within the RCUK response) given the importance of the subject matter.

³ See Section 7(1) for details.

to many issues arising within the field of regulating professionals. This is because the discretion much professional judgement entails is beyond the understanding of those outside of the profession, and is usually undertaken away from the visible aspects of professional practice. Self-regulation seeks to address these difficulties by having the expertise of others in the profession on hand and by seeking to guarantee the quality and integrity of those entering and remaining in the profession. To achieve this, the state strikes a bargain with the profession, whereby the profession is granted a near monopoly over the provision of its services, and it return it provides rules of conduct and associated regulatory processes.”⁴

1.2 As part of the process of self-regulation it is usual for a professional body to draw up guidelines or policies that its members must follow in the practice of their profession.

2. Genetic Testing of Children

2.1 The genetic testing of children is governed by the Clinical Genetics Society (CGS) guidelines, promulgated in 1994 following the establishment of a Working Party under the Chairmanship of Dr Angus Clarke⁵. Testing can be offered in two main contexts:

- Predictive testing
- Carrier testing

2.2 There appears to be consensus that there is nothing to be gained by offering predictive testing to those under the age of 18 for conditions where no treatment is possible (for example Huntington’s disease, an incurable, progressive adult-onset illness). However, testing for carrier status (where the individual is not affected by the condition themselves but can transmit the defective gene to their offspring) is controversial, as evidenced by the discussion that took place at the 6 July meeting. There is pressure from parents for testing for carrier status to be available to adolescents, and it seems that some clinicians find it difficult to resist parental demands for testing to be carried out.

2.3 The 1994 guidelines on carrier testing state:

“ 4. In general the working party would make a presumption against testing children to determine their carrier status, where this would be of purely reproductive significance to the child in the future. (a) [...] if the results would only be of future reproductive concern to the child, then it is wiser to defer the testing until the child is able to understand the issues and requests testing in person. (b) Where such (carrier) testing is, or has been, taking place, it would be useful to institute prospective and retrospective psychosocial evaluations of the impact of the testing on the children and their families, so that future policy can be guided by evidence rather than conjecture and anecdote”⁶

⁴ Davies (2007) 5.

⁵ Now Professor in Clinical Genetics, Cardiff University.

⁶ Clinical Genetics Society (1994)

2.4 Testing for carrier status for various genetic conditions often takes place during adolescence or young adulthood. General guidelines on genetic testing that discuss carrier testing in children commonly hold a broadly similar position, recommending that testing should generally be left until the child is capable of making an informed decision to be tested.⁷ However, there is still much potential for carrier testing before the legal age of adulthood at 18. Some UK guidelines specifically argue for a degree of flexibility.⁸ Additionally, careful analysis of guidelines on carrier testing in children and adolescents indicates that although it is generally advised against, this advice is worded less strongly than that for childhood predictive testing of adult onset conditions. Hence it is potentially more easily overridden.⁹ Moreover, it is noteworthy that policy statements tend to present carrier testing as a relatively minor procedure, citing that it is 'only' about reproduction rather than about one's own disease status. This potentially suggests that consent procedures could be dealt with relatively lightly.¹⁰

2.5 In discussing the appropriate age for carrier testing, Borry et al (2006) note that guidelines 'emphasised that the decision to test should be made by the child when he [sic] reaches reproductive age.'¹¹ 'Reproductive age' is itself a highly flexible notion: it could encompass age of first period, age of onset of fertility, age of first intercourse, or age of consciously 'trying for a family'. In our discussion of what constitutes sufficient maturity to consent to carrier testing, and how this relates to the law on consent, we will be questioning exactly how this common link of carrier testing with reproductive age is and should be made.

2.6 The age at which testing for carrier status is offered and conducted varies between institutions. At some, this is at or after the age of eighteen, but testing may also be undertaken earlier, and our data includes many instances of carrier testing well before this age. Testing may occur at around the age of fourteen or fifteen, and is often associated with the onset of puberty.

2.7 There is indeed some impetus, in policy discussion and, as our data will show, in practice, to equate age of appropriate testing with sexual maturity. The Clinical Genetics Society dismisses sexual activity as a reason for carrier testing, and suggests that pushing such testing on an adolescent is 'likely to generate more problems than it "solves".¹² Against this, when discussing the boundaries between childhood and adulthood with reference to genetic testing, the Genetic Interest Group states: 'The age at which a young person becomes sexually active might be a better indicator than any fixed age. It is certainly the age at which genetic information becomes important in many circumstances'¹³, going on to add, 'In many, perhaps most, cases the issue of carrier status will be best dealt with at puberty or when the child becomes sexually active.'¹⁴ Commentary on this indeed suggests that carrier testing before sexual

⁷ A useful overview of these guidelines is given by Borry et al (2006).

⁸ British Medical Association 1998, Genetic Interest Group 1995.

⁹ Hogben and Boddington 2005.

¹⁰ Hogben and Boddington 2005

¹¹ Borry *et al* 2006: 134).

¹² Clinical Genetics Society, 1994: 793.

¹³ Genetic Interest Group, 1995: 2

¹⁴ Genetic Interest Group, 1995: 4

maturity or activity is actually advisable: 'Facts of life are best absorbed slowly and when the moment is right than during a crisis over a pregnancy.'¹⁵

2.8 We are concerned that there seems evidence that in at least some instances, the Gillick ruling may have contributed to a presumption of a lowered age of consent to carrier testing, perhaps linked with onset of puberty. As we go on to discuss, this would not be a faithful interpretation of Gillick, and there are reasons to consider that neither does it represent good practice, if applied generally.

3. Benefits and disadvantages of testing at different ages

3.1 Discussion of the advantages and disadvantages of carrier testing in childhood focuses upon concern for the child's autonomy, including the possible compromise of confidentiality, and upon assessing possible harms and benefits, including psychological ones.¹⁶ Whilst our concerns here have particular relevance for issues of autonomy, they also take a different perspective: the effectiveness of such testing. There are grounds for considering that in at least some instances, adolescents may have a reduced capacity to understand these tests and their implications compared with adults, and that moreover there is some evidence that this reduced capacity may escape detection. The purpose of the tests, to provide information in a form that is assimilated and available for future practical use, therefore could be compromised.

3.2 The benefits and disadvantages of carrier testing at different ages are often discussed in relation to certainty. If carrier testing is performed at adolescence or adulthood, this has the consequence that potential carriers, and their parents, may grow up uncertain about whether or not they have inherited the relevant gene, and thus whether they are able to pass it on to their children. Parents too may feel uncertainty and associated concern for their children, sometimes accompanied by guilt.¹⁷ The pressures of such uncertainty may be used as a reason for earlier testing. There are also many instances where children have grown up without any knowledge of the condition, or with any notion that they might be affected by it, and so cannot be said to 'suffer' from any uncertainty in relation to it.

3.3 The resolution of uncertainty may thus act as a reason for earlier testing, and therefore as a reason to carry out testing in adolescence sooner rather than later. This makes the obvious assumption that carrier testing provides information which gives rise to knowledge that resolves the uncertainty. However, there are many reasons to question any simplistic equation of the provision of information with the acquisition of accurate and usable knowledge and, as we shall argue from an examination of data arising from a recent research project,¹⁸ many reasons to think that carrier testing during adolescence may well fail to translate into effective understanding. If this is absent or incomplete, a substantial reason for earlier testing is defeated.

¹⁵ Gillot, 1998: 99

¹⁶ (McConkie-Rosell and Spiridigliozzi, 2004; Hogben and Boddington, 2005; Borry et al, 2006)

¹⁷ McDaniel, 2005; Hallowell et al, 2006; James et al, 2006; Lynch et al, 2006, Featherstone et al, 2007.

¹⁸ 'The Transgenerational Communication of Genetic Information', funded by The Wellcome Trust (2004-7), which was undertaken as part of the programme of work of the ESRC Centre for the Social and Economic Aspects of Genomics (a collaboration between Lancaster and Cardiff Universities).

3.4 There are many reasons for caution in considering the effectiveness of genetic counselling in this age group. Gaff et al (2006) discuss how the ability to think abstractly, the necessary self-awareness for applying abstract notions, such as risk, to one's own position, and the capacity to think about both long and short term consequences develop during adolescence at varying speed. These factors, as well as the absence of transferable life experiences, may add to the difficulty of genetic counselling for adolescents. The lack of relevant life experiences to ground abstract notions in concrete and personalised reality is a general factor in the ability to comprehend genetic information¹⁹ and hence a particular potential problem in providing genetic tests to young people.

4. The Gillick ruling and competence to consent to medical treatment

4.1 Space constraints do not permit a detailed discussion of UK law on consent to medical treatment and the effect of the Gillick judgement, although this can be provided. An examination of the judgement shows that it replaces a 'status' approach²⁰ to capacity to consent to medical treatment with a functional approach, which makes 'ability to understand' the basis for capacity or competence to make a decision. Following Gillick, the General Medical Council guidelines emphasise that the judgement of whether patients are capable of giving or withholding consent to treatment or disclosure must be based on an assessment of their ability to appreciate what the treatment or advice sought may involve and not solely on their age (General Medical Council 1998: 23). The Law Commission also adopted the functional test in its report Mental Capacity (Law Commission 1995) which is now incorporated into the Mental Capacity Act 2005.

4.2 The Gillick ruling thus made clear that there should not be a blanket rule about capacity to consent based upon age or any other criterion, but each case should be considered individually based upon a judgement of 'sufficient understanding'. This will depend upon differences between individual persons, and also differences between procedures should be considered.

4.3 So, how would this approach to capacity testing apply to genetic carrier testing? McHale considers that 'given that the implications of such a test may be considerable, it is likely that a high level of maturity would be required before the child will be held to be competent to testing/screening without the knowledge of his parents or against their express wishes'²¹ (1997: 6). We are not here concerned *per se* with cases of child/parent conflict, but with what level of maturity is needed for truly adequate consent, which this opinion would set as high. As well as theoretical reasons for requiring such a high level of maturity, we have evidence from considering our interview data that tends to confirm this view.

5. What level of understanding is desirable for carrier status testing?

5.1 Lord Scarman in Gillick talks of the kinds of things a girl needs to understand in relation to contraceptive advice and treatment. '...[T]here is much that has to be understood by a girl under the age of 16 if she is to have legal capacity to consent to

¹⁹ Gregory and Boddington, forthcoming

²⁰ A 'status' approach to judgements of competence is one based upon some attribute of the person such as age.

²¹ McHale, 1997:6.

such treatment. It is not enough that she should understand the nature of the advice that is being given: she must also have sufficient maturity to understand what is involved. There are moral and family questions, especially her relationship with her parents; long term problems associated with the emotional impact of pregnancy and its termination; and there are risks to health of sexual intercourse at her age, risks which contraception may diminish but cannot eliminate.' (646)

5.2 This spectrum of concerns contained in this statement also presents itself with regard to carrier testing. It is important to remember that the staged growth to maturity emphasised by Gillick is not only staged, it is multidimensional, and maturity may be reached on some elements and not on others. It is salutary to consider, that insofar as a girl under the age of sixteen may be judged sufficiently mature to consent to contraceptive prescription, this is against a background of the perceived importance of providing such a safeguard, recognising that most girls of this age, at least in modern Western societies, manifestly *lack* the maturity for motherhood.

5.3 Likewise, we would argue that elements of the maturity needed to consent to carrier testing may be present, whilst others may be absent. In particular, we are concerned with how this mixed picture might impact upon carrier testing as good medical practice, given that a *sine qua non* of such practice is the ability to digest and retain the information and its personal implications for much later use.

6. The research findings

6.1 Our research on family communication (see footnote 2) was designed to address questions of when and how parents discuss issues relating to familial disease with, *inter alia*, their offspring. Several conditions were investigated but our focus here is upon the data relating to haemophilia.

Whose knowledge is it anyway?

6.2 Some of our data indicate that testing of adolescents (or indeed younger children) is motivated by concern not of the child, but of the parents. This is particularly the case in respect of the mother. That the prompt to test might originate from the parents rather than the child might in itself seem unproblematic. However, there are strong grounds to consider that it is crucial that the impetus comes from the child, because of the importance of that child being ready to receive and make sense of test result information for the test to fulfil its purpose.

6.3 In our interview data it is clear that some of the adolescents tested for carrier status were not in fact able to assimilate the information that the test result provided. We have examples of people having been able to convince the clinic that they understood the issues and were able to make an autonomous decision to have a test, but who looked back and said that, with hindsight, it was too early for them.

Sexual maturity and pregnancy concerns

6.4 Our data indicate that in at least some instances, testing is taking place when a female child lacks sufficient maturity; physical maturity may develop at a faster pace than emotional maturity. Even when an adolescent girl is emotionally mature for her age, she may not be ready to think through the implications of reproduction, which for

most adolescents is a topic that belongs to a different stage in the life cycle. However, we also have data indicating that pressures to test at adolescence exist. It may be possible that different forms of maturity are being conflated: physical maturity (evidenced by the onset of menarche) and the potential for sexual activity, on the one hand, and the reflective future-oriented maturity needed to consider fully the ramifications of a positive test result.

6.5 In discussion, some interviewees made an explicit link between the age of sexual maturity and the need for their daughter to be tested to ascertain their carrier status. Even where an explicit connection between the onset of puberty and testing was not made, our data show that for some parents who were interviewed the link with possible sexual activity was a factor that they took into account in considering the timing of communicating risk status.

7. Meeting: ‘Genetic Testing of Children: How should we decide?’: 6 July 2007

7.1 In July 2007 the British Medical Association held a one-day conference entitled ‘Genetic Testing of Children: How should we decide?’ The event was supported by the Wellcome Trust and was organised in association with the Genetic Interest Group, the Society for Genomics Policy and Population Health, the Clinical Genetics Society and the Centre for Economic and Social Aspects of Genomics. The conference was advertised as an opportunity for all interested professionals, families and researchers to meet and discuss the way forward, including the potential need for the revision of the CGS guidelines on genetic testing of children. The authors attended the conference and presented a written briefing on the research on which this evidence is based.

7.2 The conference served to highlight (both through presentation of research and the contribution of clinicians to the discussion that took place) that the CGS guidelines on carrier testing are not being observed. It appears that clinicians do not construct ‘child/children’ in a way that equates with UK law which provides that a person reaches adulthood at the age of 18. Before that milestone is reached a person has the status of ‘child’ or ‘minor’. As a consequence, the CGS guidelines, which presume against testing children for carrier status, should be applied. However it would seem from those proceedings that health professionals wish to continue to have maximum flexibility and autonomy in this area and were resistant to suggestions that the guidelines on carrier testing should be applied.

8. Discussion of issues

8.1 Our interview data suggest that in some instances at least, it seems that clinics are not actually applying the Gillick ruling, which rests on a rebuttable presumption of lack of competence to consent for under sixteen-year-olds, and requires consideration of individual cases. Rather, it seems there may sometimes be a general lowering of the age of consent to carrier testing. There may in effect be a ‘status’ approach to capacity to consent, whereby it is in effect assumed that younger girls are capable of consenting to carrier testing. This may partly result from a perception that the decision to conduct carrier testing is relatively unproblematic and that consenting to it a correspondingly less weighty. There is also some evidence to suggest that in some instances the onset of puberty may be seen to indicate adequate maturity to consent to test. However, to assume this without careful checking in each case is to conflate

different aspects of sexual and emotional maturity, and runs counter to advice in the Gillick judgement that discusses diverse factors in a child's development.

8.2 Recent research reporting a survey of 177 clinicians in the 27 European Union member states provides strong corroboration of the findings from our interview-based study²². This study asked clinicians questions about the age at which they would recommend informing children of their genetic risk of carrier status; the age at which minors should be allowed to request carrier tests with parental consent; and the age at which minors should be allowed to request carrier tests without parental consent. For all questions, the UK clinicians gave on average, lower ages than any other country, often roughly two years below the European average. For example, age for allowing carrier testing without parental consent was 16.89 for Europe as a whole, but 14.79 for the UK. From such a survey it is not possible to be sure why this difference from the rest of Europe might exist, but we speculate that the influence of the Gillick ruling could well be a factor.

8.3 Second, it seems that in some cases, even to the extent that the Gillick ruling is relied upon, its application may be flawed. The Gillick judgement makes clear that intellectual understanding alone is not enough. Many adolescents may not actually have adequate maturity in the appropriate areas of development and hence the understanding needed to consent, despite sometimes appearing to understand. Comprehending genetic information and its implications requires not just an adequate level of intelligence, but, as we have argued elsewhere, the grounded experience and maturity to make sense of the information and relate its implications to one's own life²³. Relevance is a key issue in health information assimilation.²⁴ At times, certain health information may be ignored in ways that may seem 'irrational', but which might be far more reasonable once the specific concerns of the individual and their own position in the life-course was taken into account.

8.4 From the analysis of our research data we have examples of mothers who wished to have reassurance that they had not passed on the gene, of young women who admitted that they did not understand enough about their clinic consultation to bring that knowledge to bear on their life, and of parents who either explicitly or implicitly made a connection between potential adolescent sexual activity and the need for the carrier status test to be undertaken. These factors, taken together, suggest that attention needs to be paid to the purpose of testing adolescent girls.

8.5 Any legally valid consent requires the ability to comprehend *and retain* relevant information²⁵. In the case of genetic carrier testing, especially in adolescence where very few are considering embarking on parenthood immediately, the point of the whole procedure is to provide information that will be used in the future. Hence, long-term recall and understanding is of the essence. Having babies is not uppermost in the minds of most adolescents, even though a minority see motherhood as a desirable

²² Borry et al, forthcoming

²³ Gregory and Boddington, forthcoming

²⁴ For example Backett and Davison (1992), in a study of the relevance of health advice to the general population, argue that account needs to be taken of the particular social and structural contexts of individuals and, specifically, a person's position in the lifecourse

²⁵ Re C 1992, our emphasis

outcome with status implications²⁶ There is evidence from our data that if information is not seen as salient, it is less easily digested and less easily recalled.

8.6 Furthermore, this must be considered against a benchmark of generally relatively low levels of understanding of medical information. There are many studies that show that patients may have low levels of recall of information given to them in the process of obtaining informed consent to a procedure. Moreover, there is evidence that genetic information in particular may sometimes be poorly understood²⁷ In addition, data discussed above indicate that patients may fail to understand information even at the time of consultation regarding carrier testing, and that on occasion, this lack of understanding may go unnoticed by the professionals involved. This should give rise to caution in applying the Gillick test which requires individual consideration of adolescents presenting for carrier tests.

8.7 The data suggest that there is a link in parents' minds with the onset of physical maturity, potential pregnancy, and carrier testing. It appears that this rests on a belief that knowledge of carrier status will be utilised in modifying behaviour. We suspect that familiarity with the idea of the 'Gillick competent' child, especially in relation to sexual development, may also drive the link between growing physical maturity and carrier testing. Our data however indicate quite strongly that some adolescents are not yet able to assimilate and use this information, and do not see it as relevant to their particular life stage. This is consistent with a very large body of data on adolescent sexual behaviour and risk-taking.

8.8 Integrating knowledge into personal life is an essential part of weighing all relevant factors in reaching decisions. UK law on capacity to consent requires the ability to understand the relevant information, to retain that information, to use or weigh that information as part of the process in coming to the decision, and to communicate the decision by whatever means²⁸ However carrier testing during adolescence may in at least some instances, fail to reach this standard. But how well can adolescents weigh information relevant to carrier testing?

8.9 We would suggest that, given the multiplicity of factors that are present in any given sexual encounter, the addition of the known risk of producing a child that may potentially have an inherited disease is likely to be of little deterrent to risk-taking in adolescent sexual relations. Our data suggest that, looking back to testing during adolescence, some consider they did not really appreciate the import of their test results. As a consequence, the imperative for an adolescent to be told that she is a carrier of a disease-producing gene would appear to be based on an over-simplified account of complex behaviour.

8.10 As we argue above, the individual must be sufficiently mature to integrate knowledge of her carrier status into her personal understanding of the implications that it has for her own future. Carrier testing in adolescence may then not represent a harm to the child, but it neither may it represent an effective good.

²⁶ Cater and Coleman, 2006; Coleman and Cater, 2006.

²⁷ Skene, 1998; Gregory and Boddington, forthcoming

²⁸ Mental Capacity Act 2005.

9. Conclusions

9.1 To conduct carrier testing on some cut-off point of 'sexual maturity' is to impose an adult concern on the girls. To be ready to assimilate information in a usable way, it is important that the person being tested has understood the significance of a test and sees its relevance to their lives. An adult with parental responsibility can perfectly legally agree to a carrier test for a person under the age of 16. However, the whole purpose of carrier testing is to provide usable information, and this is most satisfied if the impetus for a test comes from the young person him or herself. Carrier testing during adolescence does not necessarily reflect a time when it is best for the person to digest the information. This requires 'readiness to receive' information, that is, the ability to understand the relevance of it to one's current life stage. The Gillick ruling alerts us to the fact that there are many different aspects to developing maturity, even within the area of developing sexual maturity; being mature enough to start to deal with sexual relations is not equivalent to sufficient maturity to cope with reproductive decisions and information. There is a danger that in some instances, a tacit 'status' approach to capacity to consent is being used, with puberty or perceived onset of sexual maturity, however defined, being used as the status marker.

9.2 We are not making a general claim that no child under sixteen can maturely make this decision. Legal rulings as well as practical experience make it clear that there is a need to make individual judgements. However, our data do indicate that many of this age will not have the sufficient maturity to comprehend fully the purpose of carrier testing, and, that in some instances, the judgement of the clinic that they do, is flawed. The ability to draw upon test results when relevant in the future may then suffer.

9.3 Practitioners faced with requests for carrier testing on adolescents should consider whether the impetus for the test comes from the adolescent or from a parent. Where the impetus comes from parents, such testing may be perfectly compliant with the law, but may not necessarily represent good practice. Consent from the child herself, and more importantly the sophisticated understanding needed for true consent, is clinically important to fulfil the purpose of the test in supplying useable knowledge. Legal rulings on the precise nature of the maturity needed for true consent to such a procedure make clear what our data reinforces, that many different aspects of maturity need to have developed for a full appreciation of the ramifications of genetic carrier testing. Lack of such an appreciation in turn seems to be a factor in problems with long-term recall and the ability to draw upon the knowledge at an apposite time.

9.4 Our concern in this area was reinforced by the meeting held in July 2007 at BMA House. Its purpose was to examine whether the Guidelines on the Genetic Testing of Children needed to be revisited or whether they remained adequate for the purpose. The only contentious area was that of testing for carrier status. It was clear from the discussion that health professionals come under pressure from parents to undertake tests and that the onset of puberty, particularly in females, was a milestone at which testing was thought to be appropriate. It appeared from the discussion that health professionals shared parental concerns about teenage pregnancies, and, of more concern, that they regarded the terms 'child' and 'children' as referring to minors who were much younger than adolescents. Assuming that those present at the meeting were a representative sample of health professionals who are engaged in negotiations

with parents about the provision of tests for carrier status, there is cause for concern that clinicians are the appropriate people to regulate testing in this area.

9.5 We offer this evidence to the committee in response to the question ‘In what way is science and clinical policy decision-making informed by social, ethical and legal considerations?’. Our evidence addresses all three of these issues. We would be pleased to provide the Committee with further details of the research on which this paper is based, or of our evaluation of the use of the Gillick-competence test in this area. These are more fully discussed in a paper which is under review by the Journal of Genetic Counselling²⁹.

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