Birth family health history is shared with prospective adopters to help them understand a child’s future health risks. But guidelines for health professionals indicate that such third-party information should not be shared without the consent of birth parents. In practice this can be difficult to achieve. Catherine Hill and Maria Edwards’ survey of 57 adoptions sought to explore the views and experiences of adopters about the value of this information to both themselves and their child. Absence of information, particularly with respect to paternal history, was common and resulted in adverse consequences for children and an impoverished sense of identity. Adopters felt that lack of information also limited their understanding of the child and therefore their ability to offer therapeutic parenting; they were ‘parenting in the dark’. A majority expressed strong views that it was their child’s right to have this information; a minority felt that confidentiality of birth family health information should remain a paramount consideration. These data furnish the debate with an important missing dimension from those whose lives are potentially enriched or impaired by the quality of information shared.

**Introduction**

The focus of medical advice where children are to be adopted is to ensure that full information about the child’s future health risks is shared with prospective adopters so that they can commit themselves to the child with the best possible understanding of that child’s known life risks. In particular, medical advisers to adoption agencies have a responsibility to gather and interpret information about the child’s extended family. This responsibility is outlined in the Adoption Act Regulations 2005:

> The adoption agency must obtain, so far as is reasonably practicable, the information about the health of each of the child’s natural parents and his brothers and sisters (of the full blood or half-blood) . . .

Birth parents of children in need of adoption have often suffered from physical or mental illness, learning difficulty or substance misuse (Hill, 2009). These difficulties may be of direct relevance to the child, either through risks of genetic inheritance or adverse early parenting environments. Ideally, birth parents give their consent for their health information and that of their extended family to be shared with adopters in the interests of the child’s future. The BAAF Parental Health Form (Form PH) and Consent Form provide a vehicle for social workers to obtain and share this information.

However, in reality birth parents may be difficult to engage or absent. Where this is the case, doctors are placed in a difficult situation as they may nonetheless have access to this information from multiple sources: verbally from the child’s social worker, from expert reports and from the child’s medical records. Professional guidance promotes a duty to maintain the confidentiality of medical information and to withhold third-party information without the expressed consent of the party to whom this information belongs (Department for Education and Skills, 2006). The exception to this rule is where sharing of this information could be interpreted as being ‘in the public interest’, although it is unclear as to what this constitutes in this particular circumstance. Agency medical advisers are regularly faced with the dilemma of being in possession of important information about birth families but of lacking explicit consent to share this information with prospective adopters (Palmer, 2008). The aim of this survey was to furnish the debate with an important missing dimension, namely the perspective of adopters. Specifically, we aimed to understand the experiences of adopters in learning...
about their adopted child’s birth family history and their views on the relevance of this information to themselves and their adopted child.

Method
The opinions and experiences of adoptive parents were sought in January 2008. A questionnaire was circulated to about 200 adoptive parents who were staff, volunteers or trainers for Adoption UK (a national self-help charity run by and for adopters). A notice was also placed on the message-board of Adoption UK’s online community, comprising about 12,000 registered users (of whom some half to two-thirds are adoptive parents). The questionnaire comprised quantitative questions regarding the age of the adopted child, year of adoption and the nature of information received by the adopters about the birth parents. Semi-structured questions sought evidence and opinions on adopters’ personal experiences and views.

Analysis
Quantitative data were anonymised and entered into an SPSS (v16) spreadsheet. Descriptive statistics were derived for continuous data. Data were categorised for age (less than two years versus more than two years) at adoption and year adopted (1998–2008 versus earlier than 1998) and categorical group differences were explored using a chi-square (Fisher’s Exact) test. Text responses to semi-structured questions were analysed using a framework approach (Pope et al., 2000), with themes archived using a word-processing programme. Themes derived from content analysis were further refined and agreed between the two authors using an iterative approach. Data from quantitative and qualitative analyses were integrated or ‘triangulated’ in order to best understand the adopters’ experiences (Tashakkori and Teddlie, 1998).

Results
Forty-five adoptive parents responded, representing the adoption of 57 children. Adoptive parents reported on experiences of adoptions spanning 20 years from 1987 to 2008. Twenty-eight children were adopted between 1998 and 2008 and 29 prior to that date. The average age of children when placed was 3.3 years (range one month to 11 years). Twenty-three children were aged one year or less at the time of adoption and 34 were aged two years or more. The age of the child at the time of survey was on average 12 years (range 1–23 years).

Aspects of birth parent health information available to adopters
One of the most striking findings was that overall, information was available for less than 50% of birth fathers. This was a common theme in responses:

Case 47: Uncertainty about our son’s paternity has left a huge gap in knowledge about his paternal background and history . . . We are left to cope with his psychological problems with only partial knowledge of his birth family history.

Questions were asked relating to three dimensions of health information: physical health, mental health and lifestyle. For both birth mothers and birth fathers, information about mental health was less frequently available than information about physical health and lifestyle (see Figure 1).

Figure 1
Dimensions of health information available to adopters for birth mothers compared to birth fathers
Although information about parental mental health was rarely available, adopters frequently identified difficulties relating to their child’s emotional and behavioural well-being. Importantly, they identified that lack of information about birth parents had left them questioning to what extent their child’s difficulties were genetic or could be explained by the child’s early environment.

*Case 47:* Major psychological/emotional problems experienced in adolescence . . . Aspects of his personality and psychological functioning may be partly determined by his genetic make-up, but lack of medical history, especially on his father’s side, makes it difficult to determine how important genetic factors might be.

One respondent noted that the information may also be relevant to a child’s lifestyle choices as they grow up:

*Case 13:* . . . there have also been questions about his mental health and the levels of alcohol usage. My child has wanted to know about this repeatedly as she looks at her own lifestyle and health.

**Opportunity to meet a medical adviser to discuss the child**

Adopters were only given the opportunity to meet the medical adviser for a third of the children in this study. This was significantly more likely to have taken place for adoptions from 1998 onwards, 13/28, compared to earlier adoptions, 6/29 (Fisher’s Exact p = .039), reflecting the increasing trend for face-to-face counselling with the medical adviser prior to linking. In only eight of these cases did the adopters feel that the doctor was able to share all relevant information with them. One respondent was very satisfied with the information available:

*Case 21:* The medical adviser was very helpful and answered our questions very satisfactorily. There was some question about the birth mother having ADHD and the medical adviser had already spoken to an expert in this field and had arranged that we could go to see this expert if we required. We found this whole experience to be very helpful and reassuring.

However, a more common perception was that the level of information was inadequate:

*Case 42:* The adoption medical was out of date at the time of placement, which the matching panel did not notice. Also, the adoption medical adviser appears not to have been given all the information required.

One adopter identified the difficulty of not knowing what questions to ask of the medical adviser despite having access to the information, highlighting the importance of skilled counselling at this time:

*Case 50:* As far as I know, I do not think that information was held back from us at the time our son was placed as I was allowed to look through files very thoroughly. What I did not have was enough knowledge to ask really detailed medical questions. I don’t think our social workers at the time had enough of this knowledge either to adequately advise us.

Many respondents noted the difficulty of distinguishing whether information was complete, indicating lingering concerns about missing detail in their child’s family history:

*Case 35:* I believe we received most of the information we needed from our child’s social worker, foster carers and therapist, though it’s not always possible to know what else we could or should have been told.

Some adopters expressed frustration about the lack of effort made in securing family history data for children:
Case 10: It seemed to be quite acceptable that there was little information about the birth father, even though at that stage he was fully accessible and available for personal information to be sought.

Case 54: My GP and health authority lost our daughter’s records at the point of sending them back to do the name change post-adoption and no one took responsibility for finding them, each saying the other had them and telling me to follow up. They were also very casual about the importance of the records . . .

Others noted that information was shared only after the child had been placed:

Case 42: Relevant information was not revealed about the birth mother’s health and lifestyle until after placement . . . only ten months after placement did I finally receive the background medical and lifestyle information of the birth mother which meant that my child was at risk of blood-borne viruses.

Interestingly, when an adoption order has been granted, adoptive parents have the opportunity to access their child’s medical records which may contain birth family data:

Case 9: Once we adopted our son I made an appointment to view his medical records and found out more information than I had previously been told. It explained various scars and illnesses which he had already suffered. I believe this should be something that all adoptive parents should do to make themselves familiar with their child’s medical history.

Impact of family health history

While lack of information about birth family health history was a predominant theme, the extent to which the presence or absence of such information affected the lives of adopters and adopted children is obviously key to understanding its importance. A majority of adopters identified that they had experienced problems due to a lack of information in this area (see Figure 2).

Figure 2

Has lack of information about your child’s birth family history been an issue in the past?

A common experience was that of difficulty or embarrassment experienced when consulting health professionals caused by an inability to provide family history, thus serving as a reminder of the child’s adoptive status:

Case 25: Every time my child sees a health professional, we have been asked about family history and the adoption issue comes up. He also has a brother who is our birth child. When I took my birth son to the optician because of concerns about his sight, I was asked how many children I had and whether his siblings had sight problems. I then had to say that my birth son’s siblings were not related to him.

Case 45: On a more personal note, I felt quite inadequate, as a parent, because I was unable to answer the doctor’s questions regarding family history.

From a medical perspective, a pressing argument in favour of sharing birth family health information, in the absence of consent, is that the child may risk adverse health consequences should that information be withheld. Many such examples were provided by respondents. A common theme was that
of unnecessary delays in diagnosis due to lack of family history:

**Case 34:** Child is also dyslexic and further investigations showed mother is also . . . If we had known that, her condition may have been picked up earlier in school. Her case highlights the importance of having a good clear medical history which allows services to be sought at an earlier stage, i.e. dyslexia diagnosed after four years of school.

**Case 29:** If known about earlier, partial sight loss would have been prevented and treatment started earlier.

**Case 45:** Yes, my son has been under the hospital since he was seven months old for a persistent cough and breathing problems. If full access to birth family’s medical history had been available to me/doctors, this would/may have helped/speeded up assessments/treatment, etc.

More commonly, adoptive parents never obtained full birth family information and were left speculating whether or not access to such information might have made a difference to their child’s diagnosis:

**Case 48:** Our son was diagnosed with Asperger’s syndrome when 11 years. As this is often passed down the male line in extended families, the absence of any paternal medical history has been an issue. Lack of medical knowledge about his birth father leaves a huge gap in our knowledge concerning our son’s future medical health risks . . . could place him at medical risk in the future.

However, not all experiences were negative; an example was given illustrating how information about the birth family medical history had made a positive difference to the child:

**Case 30:** We have been given quite a lot of information about our children’s birth family history and we have found this very valuable. For instance . . . We know that she remains very small and slight, not because early malnutrition has had any lasting effects but because she has inherited this from her birth dad.

In practice, health information about the birth family should be compiled at the point that the child enters care and is a particular focus when the plan for the child is for a permanent placement outside of the birth family. In reality, however, relevant information continues to emerge throughout the life of both the adopted child and their birth family. In birth families, for example, the appearance of cancers through the generations may indicate the need for the child to be screened. However, this information may not be available at the time of placement. This dimension was articulated by a number of respondents:

**Case 13:** I do believe wholeheartedly that adoptive families should be given the ability to track and access information at any stage of life.

Indeed, where adoptive parents had maintained contact with birth families, examples were given of how information exchange about health matters had usefully taken place:

**Case 34:** Child has a genetic condition . . . which is found in maternal grandfather and had skipped a generation . . . It is only because she has face-to-face contact with her grandfather that we discovered they had the same condition.

An interesting example was given of how this information exchange has equal potential to benefit birth families:

**Case 29:** Serious genetic condition in the mother was only confirmed after diagnosis on our daughter . . . However, it only came to light at all because of birth mother being very open and passing on her health information in the years after the adoption . . . It precipitated open contact with the birth mother who has become very ill through the condition.
Many of the respondents identified how absence of family history directly affected their adopted child. This was particularly common where the adopted children were either in their teenage years or were young adults. Early literature on the subject of adoption noted adolescence to be a particularly important time for questioning of identity (Sorosky et al., 1975):

Case 11: . . . every time my daughter asks a question that I cannot answer it impoverishes her own personal history. The lack of information helps her to feel fragmented and more insecure about her identity.

Case 14: It is also important for the children to know their own family history and medical information. When they get to their teenage years and start studying genetics at school they can get very distressed about the fragments of history they have and they can weave these together to form a hugely distorted picture of who they are. They need to have their information clearly presented so that they can make sense of their own story and be able to take a realistic view of how their family history impacts on who they are now.

Previous studies have demonstrated that female adoptees are more likely than male adoptees to search for birth family members in adult life (Howe and Feast, 2003). Birth family history becomes particularly relevant when adult adoptees become parents themselves. A number of respondents identified this as a particularly difficult issue:

Case 13: My child has felt the lack of information – especially around mental health issues and pregnancy-related concerns. When she gave birth she was asked many questions it was not possible to answer. There were some concerns about the number of family members with special needs and we would have appreciated some understanding of the genetic factors within this.

Anticipated future difficulties relating to family health history

A majority of respondents felt that the child’s family history may be an issue in the future (see Figure 3).

Figure 3
Do you think that lack of information about your child’s birth family history may be an issue in the future?

Adopters were able to expand on their personal opinions on the topic of access to birth family health information, and strong views were expressed. Many viewed the debate from a rights-based perspective:

Case 22: I cannot imagine what it would be like not to know this information. I therefore think that, for physical and emotional reasons, adopted children should have access to more information as of right.

One respondent reported the view of her adult adopted son:

Case 10: He hasn’t ever considered the issue for himself but immediately felt that he would want the same rights to knowledge as any other person.

Others expressed a view that the welfare of the child should be a paramount consideration that should override the rights of the birth parents to confidentiality:
Case 30: ... while a lot more could be done to release relevant information with the consent of birth parents, the bottom line should be the health and well-being of the children, not the privacy of their birth parents.

Another perspective was the view that the adopters themselves had rights to this information in order to make decisions about the appropriateness of the link and to have the best chance of effective parenting:

Case 42: Relevant medical and lifestyle background of birth parents is extremely important to adoptive parents. We have to parent the children that we adopt and can only do so if we are aware of all the facts, otherwise we are parenting in the dark. There appears to be a culture that background information is not relevant and as if the children are miraculously ‘reborn’ when adopted.

Case 11: It is quite irresponsible for local authorities to ask us to parent children for whom they have information which they cannot or will not share with us ... I feel that the regulations should change about third-party confidentiality. This is ridiculous and outdated. For adopters to be empowered to parent effectively and to try to help bridge the gap between the past and the present, information, including medical information re. birth family members, should be given as a matter of course to all adopters if it exists.

These views are supported in spirit by recent case law. In 2003, the High Court judged that a local authority adoption agency fell below the reasonable standard of care when it failed to provide sufficient information about a child’s potential behavioural difficulties to the adoptive parent (A & Another v Essex County Council 2003). While this ruling promotes full sharing of available information with prospective adopters, it does not address the obstacle of sharing medical information without consent.

While comments were heavily weighted towards the need to share information irrespective of birth family consent, some respondents expressed reservations:

Case 32: My own views are conflicted because during our fertility treatment we used donor sperm, where obviously we’d have known nothing about the donor ... At least having no information means ALL possible tests get done eventually.

Case 52: I’m not sure about this one. My immediate feeling was that the children should be entitled to such information but I’m not sure how this would work in practice ... I’m not convinced that a person’s medical records should be disclosed without their permission. If my own parents chose to keep aspects of their medical history from me I don’t think I would/should have the right to that information ... Overall, I think as a matter of principle that a person’s medical records should be confidential between that person and their doctor and we should be very wary of breaking this rule. This proposal is no substitute for careful work by social services prior to adoption in liaising with and counselling the birth parents and helping them to do the best for their children. After adoption, the post-box system could be used to forward any relevant information, but again, this should be at the discretion of the birth parents. It is their information, though they might be encouraged to share it through discussion of the children’s needs.

These opposing views highlight perfectly the tensions inherent in sharing information in this unique situation. While adoption law suggests that the child’s welfare should be paramount, and case law (A & Another v Essex County Council 2003) places a responsibility on local authorities to fully inform prospective adopters about the child, guidelines on medical confidentiality discourage information sharing without the consent of the birth parent (Department for Education and Skills, 2006).
Summary
This is the first study to our knowledge that has attempted to understand the relevance of birth family history to adoptive families. The majority of adopters in this study had experienced a lack of information, particularly with respect to birth fathers. Only a minority had received counselling from a medical adviser to help them understand the child's health inheritance, although this was more likely to have happened for adoptions in the past decade, perhaps reflecting a practice change.

Numerous examples were provided of how lack of family history had disadvantaged a child due to late diagnosis of conditions that might have been detected earlier had full information been available. Standard medical history-taking for a child involves questions about family history and a number of respondents found that the inability to provide this information confidently stigmatised their child in medical consultations. Adopters had a broad view of health and felt that more information about parental personality, behaviour and learning abilities, as well as genetic or medical diagnoses, would have helped them better understand their child.

Examples were given where continued contact with birth families had been helpful in understanding the child's difficulties. The value of contact in promoting such information exchange has been noted by previous authors (Siegel, 2003). Interestingly, a common theme was that of the child's sense of identity, reflecting the early work of Sants (1964), who described the genealogical bewilderment and psychological trauma experienced by adoptees who had been raised in ignorance of their genetic identity. While health history is only a small part of that inheritance, it is clearly important. Rhona Cameron, Scottish comedienne and adoptee, reported that her first question on meeting her birth mother was about her family medical history: 'I asked about relatives, what diseases they had (I have always been a hypochondriac)' (2007).

Many adoptive parents expressed strong views about the need for a more liberal practice in the sharing of information about birth family history and the child's right to understand all aspects of their health inheritance.

This study has inherent limitations that should be acknowledged. The sample of respondents was self-selecting and may have been biased. Nonetheless, in the light of the number of adoption experiences studied, these data have inherent validity. The analysis and interpretation of data sought to avoid observer bias and importantly represented all dissenting views in sample text format.

Implications for practice
A number of implications for practice can be drawn from this work. First, every effort should be made to obtain written consent from birth families to access and share their family history. The earlier this can be achieved, the better the quality of information is likely to be. Ideally, consent should be obtained early in the care planning process and not left until the care plan is confirmed as adoption, by which time many birth parents hold opposing views about what is in the best interests of their child and may withdraw their cooperation.

Where information is available in files but consent is lacking to share this information, one option is to provide information in an anonymised form, for example, 'a first degree relative has diabetes'. However, this is not without risk. While the public interest test may permit sharing of information without consent, the threshold for sharing is likely to be high and would need to be tested in case law. Clearly, both adoption social workers and medical advisers need to be aware of the current legal and professional guidelines.

A positive message from this survey is that information-sharing has the potential to offer mutual benefits to adoptive families and birth families, particularly where this sharing continues post-adoption. If this message could be rein-
forced, birth families may be encouraged to share more information. Social care staff facilitating contact and information exchange should also promote these times as an opportunity to update both parties regarding health issues.

Adopters reported positive experiences of meeting medical advisers to discuss their child’s health inheritance. Many but not all medical advisers offer this service. This study highlights the type of information that adopters find useful but also underlines the expertise required to gather and interpret this information. Published job descriptions for medical advisers to adoption agencies note: ‘It is good practice for the MA to share all appropriate information with prospective adopters and to meet with them to discuss the needs of the child/ren with whom they are matched. It is also good practice to provide a written report of this meeting’ (BAAF, 2008). Medical advisers should ensure they have time built into their job plans to give this work the attention it deserves, and the training and expertise necessary to be effective.

Importantly, and irrespective of consent, what emerges from this study is the range of information that adopters, and the child in turn, find valuable. A clear message was that adopters valued health information in its broadest context, including information that is unlikely to be viewed as ‘in the public interest’ to share, for example, a family history of dyslexia. This study furnishes the debate with reasons why such information is valuable and touches on issues such as the child’s identity and adopters’ acceptance of the child as they are.

Finally, it is clear that current professional guidelines and data protection legislation are at odds with contemporary adoption practice. A majority of medical advisers at the 2008 annual Health Group Conference indicated that they regularly shared information from children’s records with prospective adopters without explicit consent from birth parents (Palmer, 2008). The only way this can be fully resolved is through the development of specific guidelines for medical advisers approved by the relevant professional bodies and government. We hope that best practice guidance will be developed to clarify this area of work for health professionals such that they can share information of value to the child and their adoptive family while maintaining the confidence of birth families.

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