

# Grasping the Nettle: The GP, The Child and Information Sharing;

## Report from the Workshop held on 27 January 2004

### Background

1. The Department of Health asked the RCGP to respond to the recommendation No 86 of the Victoria Climbié Inquiry:

*The Department of Health should invite the Royal College of General Practitioners to explore the feasibility of extending the process of new child patient registrations to include gathering information on wider social and developmental issues likely to affect the welfare of the child, for example their living conditions and their school attendance. (paragraph 12.29)*

2. In order to respond, the RCGP organised a workshop to explore this recommendation in the context of both the Inquiry and current and emerging policy. To respond to the recommendation we needed to explore other situations in which information may be gathered. Children may not move and therefore not have a new patient check; new patient checks will not be a New Contract requirement and there are many other opportunities for information gathering. We also needed to be clear about what information we might gather, with whom we share this information and under what circumstances.
3. In terms of context, we also need to consider that this is a time of great change in child health. The last year has seen the publication of the Victoria Climbié Inquiry (1), *Getting the Right Start: National Service Framework for Children, Young People and Maternity Services - Emerging Findings*. (2), the Government Green Paper (*Every Child Matters*) (3), The Government's response to the Victoria Climbié Inquiry and Joint Chief Inspector's Report (*Keeping Children Safe*) (4) and information sharing guidance contained in *'What to do if you're worried a child is being abused'* (5).
4. A seminar was consequently arranged with the following aims and objectives:

Aim: To explore recommendation No 86 of the Victoria Climbié Inquiry and report on this to RCGP Council.

Objectives:

- To explore issues regarding information gathering and sharing information regarding vulnerable children and their families identified in government reports and serious case reviews.
- To identify blocks and barriers for GPs in information gathering and sharing.
- To consider the information GPs can gather about vulnerable children and their families.
- To explore ways in which these issues can be addressed by GPs.

## The Participants

5. Workshop participants were selected from a range of health and social care backgrounds for their specialist knowledge and interests. They were invited to attend an all day workshop at the RCGP.

Michael Bannon (Post Graduate Dean, Oxford), Yvonne Carter (Vice Dean, Warwick Medical School), Dick Churchill, (GP, Vice Chair, Adolescent Task Group, RCGP), Iona Heath (GP, Chair Ethics Committee RCGP), Chris Hirst (DfES), Lisa Reay (DfES), Mustafa Kapasi (GP and GPC member), Simon Lenton (paediatrician, Department of Health representative), Peter Mackenzie (GP, MPS representative), Andrew Mowat (GP and Named GP for child protection), Lucy Thorpe (NSPCC), Tina Ambury (GP and Vice Chair RCGP Council). Jan Horwath (Organiser and Facilitator, Senior Lecturer Social Work Studies, Sheffield University) and Ruth Bastable (Organiser, GP and Named GP for child protection).

6. Workshop participants were provided with:
  - A briefing paper stating the aims and objectives of the day, the origin of recommendation No 86 as it relates to Victoria's story, summaries of the current policy context (Green Paper, Children's Trusts, NSF, Information Sharing/IRT) and the recently published *Health for All Children* (8)
  - References to existing guidance concerning confidentiality.

## Summary of Workshop

7. This report draws on the comments of the participants who attended the workshop in response to the role-play ('Making it Real'); the presentations made at the workshop and the briefing paper and associated documents sent to participants prior to the workshop

### Setting the Scene; The broader context; different perspectives

8. The workshop commenced with presentations that highlighted the policy context in which the seminar was taking place and current practice issues. The following perspectives were explored:

#### A) *The Department of Health:*

9. There is a clear expectation by the Department of Health (DH) that professionals will work together, both to safeguard children where there is a child protection concern, and to promote their welfare where there are lesser, but not less important, concerns about a child's welfare. This expectation concerns prevention, detection, intervention and subsequent management. Increasingly, there is an expectation that assessments should be made in a multidisciplinary setting. The role of the GP is regarded as important, both because of their potential ability to recognise problems early in their course, and because of the family context in which they work. Information sharing, through the E record, and through initiatives such as the Integrated Children's System are regarded as key.

10. The DH has now accepted almost all of the recommendations from the Laming Inquiry into the death of Victoria Climbié, fully, in part or in principle. Following the publication of the Inquiry, the government responded very rapidly and clearly about information sharing where there are child welfare concerns (i.e., not just confined to child protection concerns). With respect to information sharing, emphasis is laid upon the need of all practitioners working with children to share information, as it is only then that a child will be seen to be in need or at risk of harm. There is a clear message that information should be shared, whether the case is believed to be potentially a child protection one or a child in need i.e. at a lower threshold. The view of the DH is that express consent is not needed if the information is *'trivial or readily available from other sources or if the person to whom it relates would not have an interest in keeping it secret.'* Or, *'if you have reasonable grounds to believe that the person to whom the duty is owed understands and accepts that the information will be disclosed'*. (5) The DH view is that there is no difference between the approach to confidential information sharing within an agency, such as health, and between agencies, such as health and social services.

*B) DfES: The Green Paper (Every Child Matters) and Identification, Referral and Tracking:*

11. Although children at risk of child abuse have an important place in the Green Paper, the focus is on children at risk of underachieving because of their social circumstances. Information sharing is key to the proposed changes. It is proposed that there will be a minimum data set to which all will contribute. Data will be held electronically as part of an information hub, which will be managed by the local authority and will be available for professional access. The minimum data set would be name, age, date of birth and school. The notes would be 'flagged' if the child was 'known to' education, youth offending, social services or the police. A certain number of 'flags' would result in the child having a key worker.

12. Consultation is being sought around what else should be included that would generate a 'flag' e.g. domestic violence, mental health problems in the parents, parental imprisonment, and substance misuse. Threshold issues are acknowledged: 'There is a balance to strike between sharing enough information to help safeguard children effectively and preserving the individual's privacy'. The Government wants to prevent situations where a child does not receive the help they need because of *too rigid an interpretation of the privacy of the child and family'* [our italics]. Projects such as Identification, Referral and Tracking (IRT) will be central and the government promises that legal barriers to information sharing will be removed by 'early legislation'.

*C) The voice of the child:*

13. The welfare of the child is profoundly influenced by parenting issues such as domestic violence, drug or alcohol problems, parental mental health issues and where parents have learning disabilities. Difficulties experienced by a child in this context may persist throughout life; they may be intermittent, continuous or situational and may be transgenerational. It is not just issues related to child protection that can and will have these lasting effects.

14. Prior to the publication of *'Every Child Matters'* children were consulted on what they wanted. They identified very similar issues to those identified in the Green Paper itself: the importance of being healthy, staying safe, enjoying and achieving, making a positive contribution and economic well being.
15. Many of the findings from the Victoria Climbié inquiry are generalisable. Lord Laming commented with frustration on the amount of energy practitioners devoted to whether a case was section 17 (child in need) or 47 (child in need of child protection) and called for children to be thought of, and have services provided for them, on the basis of their vulnerability. It is not possible to tell without sharing information, to what extent a child is in difficulty.
16. Lord Laming also emphasised that family support and child protection are inseparable; although social services are the lead agency, they are not the only agency, and we all have an important part to play in family support as well as child protection. Interventions should be proactive, not reactive and we should be ambitious for children; it is not enough to say they are not being deliberately harmed, they need help to flourish.

*D) Regulation and statute; the GMC viewpoint:*

17. Information sharing and consent to share information is strictly regulated by the GMC. The GMC view is that;

*“the test of disclosure in the public interest should be tested by is one of **proportionality** – weighing on the one hand the privacy interests of the individual, and the benefits of to society of maintaining public trust in the a confidential medical service, against the benefits of disclosure and on the other hand the benefits which are likely to arise from disclosure of information.” (7) para 22*

We may share information under the following circumstances:

- If it is not confidential, i.e. it is already in the public domain. We must remember that all information that a GP obtains in the course of working as a doctor is confidential. It is immaterial whether the information is already in the public domain or relates to non-clinical matters such as patient addresses or phone numbers.
- With the informed consent of the patient, be it a competent child or the parent on behalf of the child.
- In the public interest. That is, where there may be a risk of death or serious harm to the patient or others if the information is not disclosed.
- Where the court has ordered that information should be given.

The issue is one of what might constitute ‘serious harm’ in any particular case. In *Confidentiality: Protecting and Providing Information*. (Para. 29). Doctors are advised;

*Disclosures where a patient may be a victim of neglect or abuse*

*If you believe a patient to be a victim of neglect or physical, sexual or emotional abuse and that the patient cannot give or withhold consent to disclosure, you must give information promptly to an appropriate responsible person or statutory agency, where you believe that the disclosure is in the patient’s best interests. If, for any reason, you believe that disclosure of information is not in the best*

*interests of an abused or neglected patient, you should discuss the issues with an experienced colleague. If you decide not to disclose information, you must be prepared to justify your decision.*

18. Should such a situation arise in the case of a child and the doctor decides against disclosure, the GMC requires the doctor to justify that decision. In children and vulnerable people therefore, the normal weighting against disclosure is reversed.

### **‘Making it real’: Identifying Dilemmas for GPs when Gathering and Sharing Information about a Vulnerable Child and their Family**

19. The first part of the seminar was devoted to exploring the type of information a GP can elicit from a patient and strategies for both using and sharing the knowledge gained. This was done using an actor as a patient and providing opportunities for participants to ‘interview’ a patient. The consultation was information rich; using everyday consultation skills, a great deal of information was elicited within the space of a normal consultation time. Participants organised the information gathered using the *Framework for the Assessment of Children and their Families*. (6)

#### Louise’ Story:

Louise, is a young woman with two small children Jason aged 3 and Kylie aged 6, living in very cramped conditions in her mother’s small flat. Also in the flat is her mother’s boyfriend, who has a drinking problem and is violent towards her mother. Louise has temporarily left her husband as their house has been repossessed. Her husband’s gambling problem has caused debts. Louise has been married before, the relationship ended when her husband physically abused Kylie when she was a baby. Kylie was on the child protection register and in foster care for a short time. Recently, Kylie has been having difficulty at school as she has been using very offensive language to her fellow pupils and teacher. Jason is ready and eligible for nursery school, but can’t get a place. He is having problems sleeping and Louise would like some medicine to help with that. More recently, both children have been on the child protection register, though are now off it. Louise is coming to see you to request more antidepressants (these have been helpful and she has been on them for 2 weeks now) and to ask you for a supporting letter for housing. She is a pleasant young woman, she is happy to be seeing you and she thinks well of the practice.

20. This exercise highlighted some important dilemmas

#### *Wait Vs Act*

21. Exploring the child protection issues at this consultation might risk driving Louise away. GPs were willing to contain a difficult situation, to wait and see, and to build a trusting relationship, believing in the power for good of the relationship itself.
22. However, doctors are becoming less willing to ‘wait and see’ as they are being obliged to practice more defensively, particularly in the field of child protection. The dilemma for GPs is a risk of public censure and pillory when things go wrong, balanced against risk of censure from being perceived as behaving too actively.

*The needs of the adult Vs the needs of the child:*

23. In general practice, balancing the needs and wishes of the parent with those of the child is exceptionally difficult. There is a positive professional duty to follow-up children in special circumstances (not just children in need of child protection) and to ensure that steps are taken to protect them. However, it is most often the case that access to the child, whose views the doctor wants to seek, is dependent upon the parent. As GPs, we have to work through the parent. If this relationship breaks down or cannot be sustained, there is a danger that contact with the child will be lost. Ultimately, the parent is free to go elsewhere.
24. Doctors tend to want to “wait and see,” to work with the patient, but where the adult and child are both patients there is a danger that this works in favour of the adult and the child’s needs are set aside. The risk is that an already vulnerable child, with limited ability to express his or her needs, yet in need of help, can have their needs subsumed by the relationship between the parent and the professional. We wish to continue to care for children in the context of the family, but how do we do this and do the best for children and their families, not just the best for the grown ups?

*Valuing and preserving the nature of general practice Vs keeping up with new developments:*

25. General practice is committed to high standards of care; it provides an accessible and non-stigmatising service. It has a high standard of confidentiality and has privileged and usually welcomed access to the child, the parent and the wider family, within their home environment.
26. Although there is general erosion of public trust in state institutions, the public still overwhelmingly trusts their GP. New developments, such as Children’s Trusts may risk the GP being cut off from regular dialogue with colleagues about children. One of the strengths of general practice is that children are cared for in the context of their families.

*Preserving patient trust Vs working in a multi-disciplinary or interagency context:*

27. Information gathering and sharing may risk eroding an important confidential service. Patients may risk being driven away, and some of those driven away may be those most in need of help, for example, illegal immigrants. If the patient perceives that GPs share information, patients may be less willing to come to GPs with difficult and sensitive issues.
28. Because of this, it was felt that there should not be a *compulsion* to gather or share information about children’s wider social and developmental issues that has been obtained in the context of a relationship of confidence. Similarly, new patient checks and information gathering should not be a *requirement* for registration or continued registration for the same reason. Primary care does a great deal to prevent harm to children, but much of this work is invisible; general practice helps prevent adverse effects, but this is not usually measured and may be very difficult to measure. We risk losing the chance to help families and bring about good outcomes, if people are frightened to confide in their doctors. For this reason, mandatory reporting was felt to be counter-productive.

*The need to work strictly within the regulatory framework Vs the need to share information;*

29. GPs work within a strict regulatory framework. Information sharing needs informed consent and this requires us to know what information will be shared, with whom and for what purpose. Proposed developments with strong local interpretation regarding information gathering and sharing, such as IRT, raise concerns about the safeguarding of such information. There is a lack of clarity regarding what information will be stored, exactly how and accessed by whom.
30. Whilst 'children in need' are not specifically referred to within the regulatory framework, in "Confidentiality: Protecting and Providing Information" (7) paragraphs 27-29 allow a GP to disclose information without consent of his child patient if:
- Failure to disclose might put the child or others at risk of death or serious harm. (i.e. if there is a possibility of the child suffering harm, the GP should disclose the relevant information promptly to the appropriate authority. (para 27 – try and get consent first)
  - The child is incompetent and disclosure is in their medical interests. (para 28 – again, try and get consent first).
  - You believe an incompetent child to be a victim of neglect or abuse.
31. Therefore if a GP has an incompetent child patient who has a medical, social or therapeutic "need" you must act in that patient's medical interest and take any action you believe to be best for your patient. A child in "need" may well fall into one of these categories above.

Disclosure without consent was viewed by the GPs present as potentially disastrous for the relationship with the patient. Set against this, is the drive for better information sharing between agencies, earlier in the course of a child's difficulties. The central conundrum remains, that we often will not know whether there is a child protection concern or not, until such time as information has been shared.

*Common standards of information sharing Vs differentiating between the PHCT and other agencies:*

32. Participants at the seminar were far less hesitant about information sharing within the primary health care team than information sharing outside that team. On the whole, GPs were willing to share concerns and seek information within the team, without the expressed consent, as this was regarded as essential and normal medical care. However, they were more hesitant to share information and seek information outside the team, on occasions markedly so and unwilling to do so without the consent of the patient, unless there was a proven or very strong suspicion of a child protection concern. GP's should ensure their patients understand that information they provide their doctor with must be shared within the health care team in order to look after them properly. Furthermore, that this information will be handled by various team members, some of them lay, but that every one of them has been trained in the principles of confidentiality. Patients must be told that if they object to this approach they should consult a named individual in the practice to explain their concerns. An example of ways for GP's

to inform patients of this are through the practice leaflet; practice website or notices in the waiting room.

33. The child protection system relies on information sharing between agencies; child protection operates in a jigsaw or patchwork manner; you don't know what you know until all the pieces are in place. Information sharing depends heavily for GPs on the presence of trust and good interprofessional relationships. The person to whom information is passed has to be trusted not to undermine the relationship with the patient and different professionals need to recognise and respect others professionalism and their different but no less valid perspectives. This relationship may not exist outside the PHCT.

*Here to listen not to tell Vs information sharing:*

34. There were especial worries over young people. On the one hand a great deal of effort has gone on in the Royal College of General Practitioners (RCGP), with DH help, to reassure young people that general practice is a confidential service. However, we are working in a climate where it is expected that we will share more information with more bodies. These two drivers are potentially in opposition. There were also concerns over consent to information share; it may be appropriate to ask the young person for consent or at least assent, rather than the parent. Seeking such consent is potentially fraught with difficulties.

*Working together Vs going it alone:*

35. Child protection is high challenge multidisciplinary, interagency work. Research evidence indicates that GPs may avoid child protection issues because of fear of aggression or violence. GPs may also wish to keep a child out of the child protection system because of a perception that it can be better managed outside the system or because of a lack of trust or lack of confidence in the effectiveness of the child protection system. However, adopting a primary care team-based approach may both provide a supportive framework for a child and family, and retain the familiarity with child protection and its associated procedures, which other agencies may possess.

### **Developing Guidance for Information Gathering and Sharing**

36. The second half of the workshop focused on developing guidance regarding the gathering and sharing of information. Working within the regulatory framework, the kind of information gathered and the expectation from and of the GP were summarised (Table 1).
37. Importantly, it was recognised that there is no such thing as non confidential information in the general practice setting; any identifiable information obtained by a GP through his work as a doctor is confidential irrespective of whether it is already in the public domain or relates to non-clinical matters such as patient addresses or phone numbers. This information cannot be shared with anyone without valid consent (\*note there are several exceptions e.g.: public health notifiable diseases). This view is in line with GMC advice on this matter; the GMC advice is that "all information disclosed to doctors is confidential and, in some cases, for example for women suffering abuse from partners, addresses can be

sensitive data and patients can have real concerns about who has access to this information.” (7) GPs especially emphasised the difference between sharing with an IT database, such as those used in Information Referral and Tracking (IRT) pilot projects where there is little understanding on the part of the GP regarding who will have access to the information and for what purposes it will be used. The IRT projects seems to distinguish between ‘routine’ information, such as name, age, date of birth and school which is in the public domain and ‘sensitive’ information which would not be shared unless consent has been obtained or it is in the public interest to share if consent is not obtained. However, there is no information the surgery can disclose about a patient to a third party, even if, like name and address it is already in the public domain. This information is confidential as it is part of the patient’s records and has been obtained within the context of a relationship of confidence. There was a concern that even very basic data could be highly confidential and that might not be appreciated by someone else accessing the database.

38. Information cannot be shared by GPs without consent unless there is a risk of serious harm or death (see paragraph 16). The threshold for sharing without consent is high even where disclosure is presumed to be in the best interests of the child and non-disclosure will need to be justified. Whilst the GMC’s response to the Green Paper, *Every Child Matters* makes clear that they support sharing of information to protect children from neglect or abuse, whether or not a parent or child consents to this, they are more equivocal about sharing ‘causes for concern’ where there are no issues which would warrant further assessment or intervention to protect a child from harm. The GMC believes that considerable effort should be made to gain the agreement of children and their carers to the disclosure of information to IRT or comparable systems. Furthermore, the GMC is concerned that information passed on without consent might dissuade some carers and children from coming forward to seek help at a stage when problems could be managed and resolved.
39. It is recognised that the domains and range of information elicited by GPs, and other members of the PHCT, will often differ from that elicited by other agencies, even utilising an approach based on the Assessment Framework. Should the criteria for information sharing be met, it is appropriate to share that information pertinent to the cause for concern about a child, rather than indiscriminate disclosure of every piece of information on record about the child and their family. It will then be up to partner agencies to fill in blanks, rather than requiring GPs to go beyond their normal scope in information-gathering.
40. The process of Serious Case review, described in Part 8 of “*Working Together to Safeguard Children*”(9), gives an opportunity for all agencies to learn lessons from the death of a child, where abuse or neglect are thought to be factors in the death. The view of the GMC, expressed in “Confidentiality: Protecting and Providing Information”, (7) is that all GPs should cooperate with requests for access to information about the child and their family, even where the child’s family does not consent.

**Guidance on Gathering and Sharing Information (Table 1)**

<b>Basis for sharing information: active or passive sharing</b>	<b>Type of information</b>	<b>Expectations of professionals</b>
<b>Information not confidential</b>	No information falls into this category	Other professionals may not appreciate that even apparently trivial information, and even information already in the public domain, such as name and address, is confidential when it is obtained in the context of the doctor patient relationship.
<p><b>Parent of incompetent child gives consent to information sharing</b> The GP should ensure that the parent understands the content of the medical records; who they will be shared with and what third party may do with the information</p> <p>The GP should be convinced that it is in the best interest of the child to divulge the information</p> <p>The GP should obtain written consent from the parent or an individual with parental responsibility</p>	<p>Information about themselves and a non-competent child</p> <p>Information regarding an identifiable third party cannot be divulged without the consent of that third party</p>	<p>GP as custodian of such information should be responsible for divulging such information. They should:</p> <ul style="list-style-type: none"> <li>• Check authenticity of those making enquiry</li> <li>• Ensure a named professional has a demonstrable 'need to know'</li> <li>• Clarify of what that professional will do with the information</li> </ul> <p>GP's must remember that parents, police, solicitors have no automatic right to see a child's records. The GP must be satisfied disclosure is in the best interests of that child</p>
<p><b>Competent child gives consent to information sharing-</b> Need to be certain that the child is competent</p> <p>Must always act in the child's best interest even if this means divulging information.</p>	Information regarding an identifiable third party is not divulged	<p>Any referral should be made to someone appropriately qualified and competent</p> <p>Professionals should recognise and acknowledge different areas of expertise and each other's difficulties and perspectives when</p>

<p>If child is hesitant to parent's knowing- GP should encourage the child to share if the GP feels is in best the child's interest for parent to know. Must respect competent child's wishes.</p>		<p>sharing information.</p> <p>Professional receiving information must be aware of the limits of consent given by the patient</p> <p>GPs require feedback and dialogue during the process</p>
<p><b>In the public interest to share information</b> Must demonstrate that an attempt has been made to obtain consent of the patient to sharing information before sharing without their consent</p> <p>If non-disclosure of information might expose the patient or others to a risk death or serious harm, disclosure of the minimum amount of information necessary should be made to the appropriate authority</p>	<p>Information that indicates the patient or others might be exposed to serious harm</p>	<p>Before sharing information without consent the GP should consider:</p> <ul style="list-style-type: none"> <li>• Who would you gather information from if a suspicion arose?</li> <li>• Speaking to other colleagues within the health team to clarify situation</li> <li>• If the situation cannot be resolved- refer. Any referral should be made to someone appropriately qualified and competent</li> </ul> <p>GPs require feedback and dialogue during the process</p>
<p><b>Disclosure of information required by court</b> Profession is bound by ruling of the court</p>	<p>Information relating to court case Information as directed by the court</p>	<p>Before sharing information, GP needs to <b>remove</b> any third party information contained in the notes.</p>

## Conclusion

### The fragility of the role of the GP

41. The consultation with Louise demonstrated that a large amount of very sensitive and personal information can be elicited by a skilful GP during a single consultation. However, subsequent feedback from Louise revealed how difficult it is for her to trust agencies representing authority and how easily she can be frightened away. The more difficult and stressed her situation and the more she realises the limitations of her parenting, the more tentative she feels and the more easily frightened. The potential for a new variant of the inverse care law is

clear. Unlike schools and nurseries, GPs have no direct access to children and can only provide care to vulnerable children if they are able to establish relationships of trust with one or both parents.

### **Whose voice is loudest?**

42. The statutory and professional regulatory framework influences the view of GPs on what information can and cannot be shared. There is a clear expectation from the DH and DfES that GPs will work closely with other agencies and will share information early in the course of a family's difficulty. The recent guidance published by the DH on information sharing (5), although fully acknowledging the current regulatory framework, draws attention to the fact that information sharing where there is a section 17 inquiry, a section 47 inquiry or in connection with court proceedings is in fact covered by the same law (common law, the Human Rights Act and the Data Protection Act). Furthermore, there is no difference between disclosing information within one's own organisation and to another organisation. The need to disclose confidential information will arise less often between agencies, but the approach should be the same. This view contrasts with how the GPs perceived the view of the GMC, which allows information sharing without consent in child protection and is compounded by the ambiguity of what constitutes 'serious harm'. It also highlights the reluctance of GPs to share information outside the PHCT because they perceive it to be potentially damaging to do so.
43. It is not possible to tell without sharing information, to what extent a child is in difficulty, yet we seem to be operating in a system where information will only be shared outside the PHCT where we believe there might be a risk of harm to the child if we don't act. Disclosure is then expected (in line with paragraphs 27 - 29 of *Confidentiality: Protecting and Providing Information(7)*). The reasons for this are not just cultural, but also relate to how we interpret our professional regulatory framework.

### **Is recommendation no 86 feasible?**

44. Gathering and sharing information presents dilemmas for general practitioners; some of these are inherent to the nature of general practice. Information gathering on wider issues is feasible; however, sharing this is not straightforward.

### **Key Learning Points**

45. In particular, we must consider:
- I. **Valuing and preserving the nature of general practice:** information gathering and sharing should not be allowed to erode an important confidential service. In particular, new patient checks on children should not be a requirement of registration and there should not be a compulsion to share data gathered in this or other general practice consultations.
  - II. **Opportunities for information gathering:** these are not just dependant on new patient registration:

General practice consultations are information rich. We gather information about children and their families in the course of consultations with children, their parents and perhaps also with other members of the family. Information is not gathered solely in the context of new patient registration; continuing additions to the record should be made and shared appropriately.

### III. Rationale for professional regulation on information sharing

Information sharing in the general practice context is closely regulated. GPs and other doctors must work within current ethical and legal guidelines. All information storage and sharing is governed by professional guidance. Even apparently trivial information is confidential. We may share identifiable information if we have the informed consent of the patient to do so. Where a child is involved, we always have to consider if consent should come from the parent or child. Informed consent may not be simple or easy to obtain; patients need to know what will happen to the information gathered for consent to be valid.

GPs can and do share information in the public interest, without consent, but are strictly governed in this arena.

### IV. The GMC position on *What To Do If You Are Worried A Child Is Being Abused*.(5)

The GMC supports the description of the law at Annex 3 of this document, with minor reservations already mentioned in paragraph 37 above, surrounding the confidentiality of *all* information given to doctors.

They also support the distinction the document makes between concerns about child abuse and neglect, which should always be reported (paragraph 10.4) and, the advice to seek agreement from children and their carers for disclosures in other cases (paragraph 11.3).

The GMC is currently considering these issues and watching the passage of the Children Bill through parliament with considerable interest. Should the Secretary of State **require** disclosures of information which does not relate to risk of abuse or neglect, the GMC will change its guidance accordingly.

### V. Barriers to sharing information using information technology:

Information technology potentially presents a fast and efficient highway for information sharing that apparently removes some of the barriers to information sharing. However, sharing information with an anonymous data base presents special problems in gaining informed consent from the patient. In particular, there is currently insufficient clarity regarding the way in which the information hub outlined in the Green Paper will operate. For example, what information will be held and who will have access to this information. Participants at the seminar expressed concerns over possible 'leakage' of information from this database.

Participants concluded that the vision of information being shared more freely is much harder to operationalise than it is to conceptualise.

**VI. Information sharing is only one part of the multidisciplinary assessment and intervention process**

Sharing information is only one of the steps to helping children; additional information has to be gathered from a variety of sources. This information needs to be and interpreted to identify the needs of the child and decisions made regarding services required. Effective action by a variety of professionals has to occur and resources to effect that action have to be available. This whole process is dependent on much more than effective information sharing. It requires that professionals speaking a common language understand each others roles and responsibilities and trust each other.

**VII. The professional cost of being involved with children in need:**

There is a significant professional cost to being involved with children in need and their families particularly where there is a child who is suffering or likely to suffer from significant harm. Improved information sharing is likely to lead to more assessments and interventions albeit it at a more preventative and therefore more effective level. Professional support, time to develop effective interprofessional relationships and the development of appropriate services for children and families will all be needed to make information sharing worthwhile. New ways will need to be developed to support those GPs and their practice teams who provide services tailored to the care of vulnerable children and their families.

**VIII. The needs of the child, the autonomy of the parent:**

One of the strengths of general practice is that it cares for children alongside and with the involvement of their parents and families. We rely on the engagement of the parent. Balancing the needs and wishes of the parent with the needs of the child is exceptionally difficult, inherent in the nature of general practice and will not go away.

**What would help?**

46. With respect to IRT:

- The organisations who need to obtain information about a patient from a GP need to be educated themselves as to how best approach that doctor. The College could consider helping these organisations (eg: schools or social services) understand how they should anticipate the legal shackles that prevent GP's from disclosing information to these bodies.
- Clarity based on the evaluation of IRT (Identification Referral and Tracking) pilot projects regarding what information is gathered, stored and shared, by whom it is accessed and for what purpose.
- Recognition by government who are proposing information hubs that GPs work within a national regulatory framework, local information sharing protocols may have value, but do not really assist GPs in this matter.

## References

1. Laming, Lord. *The Victoria Climbié Inquiry*. The Stationery Office, London, 2003.  
<http://www.victoria-climbié-inquiry.org.uk/finreport/downloadreport.htm>
2. Department of Health. *Getting the Right Start: National Service Framework for Children, Young People and Maternity Services - Emerging Findings*. Crown Copyright 2003  
<http://www.doh.gov.uk/nsf/children.htm>
3. Department for Education and Skills 'Every child matters' [*The Green Paper*] The Stationery Office, London. 2003 [www.dfes.gov.uk/everychildmatters](http://www.dfes.gov.uk/everychildmatters)
4. Department for Education and Skills, Department of Health, Home Office. *Keeping Children Safe: The Government's response to The Victoria Climbié Inquiry Report and Joint Chief Inspector's Report Safeguarding Children* The Stationery Office, London 2003 <http://www.dfes.gov.uk/index.htm>
5. Department of Health *What to Do If You Are Worried A Child Is Being Abused*. 2003  
<http://www.doh.gov.uk/safeguardingchildren/index.htm#intro>
6. Department of Health. *Framework for the Assessment of Children in Need and their Families*. The Stationery Office, London, 2000 <http://www.doh.gov.uk/scg/cin.htm>
7. General Medical Council. *Confidentiality: Protecting and Providing Information*. (Para. 29). London: GMC, 2004.  
<http://www.gmc-uk.org/standards/secret.htm>
8. Hall DMB, Elliman D. *Health for all Children: the report of the fourth joint working party on child health surveillance*. 4<sup>th</sup> ed. Oxford: OUP, 2003.  
<http://www.health-for-all-children.co.uk>
9. Department of Health. *Working Together to Safeguard Children*. London: TSO, 1999.  
<http://www.asylumsupport.info/publications/doh/safeguard.pdf>