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### *Is there a regional or national computerized database of patients with multiple red cell antibodies or other complex transfusion histories?*

**A Medical Director of a Transfusion Medicine Program in New York** is wondering about the feasibility of making transfusion information on highly immunized patients available regionally or nationally. She wants to know if any regional blood center in the USA or Europe has developed a computerized database of patients with multiple red cell antibodies or other complex transfusion histories that can be accessed directly by local transfusion services. Such a database might be useful to determine the special type of blood products needed by patients with complex transfusion histories who present for transfusion but with little knowledge of the medical history.

The following responses were received.

**ADDENDA** Feb. 5, 2003

1. **A colleague in Boston** is of the opinion that a national/regional database would be a wonderful idea. It could be extended to patients and their transfusion requirements as well as donors and their potential deferral. However, he points out that there is a big 'fly in the ointment', namely [HIPAA](#). In his opinion, compliance with HIPAA would probably have the effect of preventing the sharing of this type of data in an open registry.

**ADDENDA** Apr. 19, 2004

2. **A colleague in New York** reports that in the February issue of Transfusion Medicine vol 14 no 1 2004: pp 59-73, the article (no abstract listed) "Guidelines for Compatibility Procedures in Blood Transfusion Laboratories", on page 60 it states: "**Links between National Health Service (NHS) computer systems, or the growth of national databases such as those operated by the UK Blood Services accessed via a web browser, provide important opportunities for hospital transfusion laboratories to check on historical information such as red cell antibody specificity.**" He observes that it appears that our British colleagues have already begun to implement the system proposed above. He hopes that someone from the UK could educate the e-Network Forum about their system.

**ADDENDA** Apr. 20, 2004

3. **A large blood center in Texas** has been working for the last 6 months to get written agreements from their local and regional hospitals to share information on patients' antibody workups. There were **concerns about HIPAA and sharing results**, so they have chosen the route of obtaining **written mutually-agreed contracts** that allow the sharing of patient data. The shared data consists of antibody information (or other immunohematology test information) on patients whose samples are tested at the blood center's reference lab. Sometimes the patient will be treated at one hospital and then be transferred to another. Their **database would not include information from testing at the individual hospitals**, only at the blood center's reference lab.

**ADDENDA** Apr. 26, 2004

4. **A colleague at the Red Cell Immunohaematology (RCI) Reference Service in the UK** reports that the National Blood Service provides tested donor blood/components to hospitals in England, and also offers laboratories access to the services of 12 RCI laboratories throughout England. These laboratories perform routine prenatal screening and reference service

investigations for a large part of the country. The results from both the routine prenatal and reference service investigations are entered into a national database. Therefore if a patient moves from one part of the country to another and a sample is tested at a different RCI laboratory, the results (such as the antibody specificity etc), will be available on the database. Investigations performed within the hospital transfusion laboratory and not referred to a RCI lab will not be entered into this database. To allow those non-laboratory staff who have a legitimate clinical need to see the RCI results, the results are available via a Web browser. To gain access to the Web browser results, the inquiring hospital must register through a controlled process that ensures UK data protection laws are complied with and patient confidentiality is maintained. As both the NBS and hospital services are within the National Health Service this does make control of access to data easier than if dealing with different organisations.

**ADDENDA** May 5, 2004

5. **The policy in place in a transfusion service in Southern California** is to attempt to obtain the patient's transfusion history, including "where and when" they were previously transfused, whenever they encounter a positive antibody screen. If the patient was transfused at another facility, that facility is then contacted to obtain the patient's transfusion and antibody history. **Antibodies identified at other facilities are honored** even if not currently demonstrating in the Southern California colleague's hands. This policy has shown merit, and **has prevented transfusion of antigen positive units** to a patient whose antibody titer has dropped to below detectable levels. Another benefit of this policy is that knowing a patient's historical antibodies may greatly simplify the workup. The obvious downside as compared with a database, is that it relies on the patient or patient's family member to be good historians and is only initiated upon discovery of a positive antibody screen. Another consideration is to **issue an "Antibody Identification Card"** to the patient to present upon admission which states his or her multiple red cell antibodies or other complex transfusion history.

**ADDENDA** Nov. 16, 2005

6. **A chief medical scientist at a Dublin, Ireland hospital** reports that in 1999 his transfusion service laboratory began to consider the concept of maintaining a database of patients with unexpected red cell antibodies among local hospitals. After conducting a feasibility study, their concept was presented at an annual hemovigilance meeting where the value of such a database was recognized, but concerns over patient consent and data protection were also voiced. In 2001 they **opened a website which contained a live antibody database which was tested using fictitious names and data**. The operator could select antibodies from a drop down menu of predefined antibodies. The database retained a historical record of every entry and its origin. The database also had tick boxes for CMV negative and Irradiated Products. A 'notepad' was provided to record such data as phenotypes for sickle cell patients, transfusion reaction histories, problems with autoimmune hemolytic anemia (AIHA) or other miscellaneous items. The main concept of the project was to create a national transfusion database to which every hospital blood bank in the country would have access. In addition to the original reason for setting up the project, the Dublin scientist reports that another unexpected bonus emerged. According to him such a database would "allow for the establishment of national, regional and local rates of antibody detection. These could in turn serve as quality assurance indicators. Individual hospitals could benchmark their performance against any of the above and also against hospitals of similar types or patient profiles. As a result instrument, reagent or operator performance could be compared and problems identified." They feel it is a useful quality tool in addition to the use of external quality assurance material for measuring laboratory performance. He reports that the updated project was **presented at a recent hemovigilance meeting** where it received a more favorable response. This was due to the realization that reporting of delayed hemolytic transfusion reactions was on the increase. **Due to lack of funding the website was recently closed down**. However it is being proposed to the department of health by the national hemovigilance office as a worthwhile healthcare initiative. A recent **powerpoint presentation** which includes screen shots of the database can also be accessed by visiting the Irish blood transfusion service website [www.ibts.ie](http://www.ibts.ie) under the category "Our Services", by clicking on the category "Haemovigilance", then "Events", and then on the presentation by Paul O'Brien.

**ADDENDA** Nov. 20, 2005

7. **A transfusion medicine physician in New Zealand** reports that **essentially all New Zealand blood banks share the same data base**, with the exception of very small hospitals

where blood is only occasionally issued. The data base contains the following information: patient blood groups (ABO/Rh/others), presence or absence of unexpected red cell antibodies. In addition, the data base also contains patient transfusion histories (including information regarding issuance and transfusion of blood products and blood components), and details about special transfusion requirements that patients might have.

**ADDENDA** June 7, 2006

8. **A hospital blood bank coordinator in Southern California** is very concerned about the **absence of any systematic database** of patients who have had a red cell antibody identified. Her facility had a recent experience in which a patient came to their hospital for the first time, so they did not have any record on him. One of their **part-time technologists**, who was working that day, **recognized the patient's name as a frequent visitor to the hospital where she works full-time**, and alerted the blood bank supervisor to the fact that the patient has a previously identified antibody. The patient's antibody screen at the time of this occurrence was negative, and they had already crossmatched three units of ABO/Rh matched RBCs for him. Upon checking with the other hospital it was discovered that the patient had a **history of anti-Jka**. It deeply concerns the inquiring colleague that if the part time tech had not been working at her facility that day, they would have had no knowledge of the patient's previous history and they **might have provided the patient with Jka antigen-positive blood that might have caused a delayed transfusion reaction**.

**ADDENDA** June 8, 2006

9. **A colleague in Rochester, New York** reports that his hospital sends a **letter and a card to the attending physician to pass on to each patient** that they discover to have an unexpected red cell antibody. As far as the respondent knows (and they have followed this practice for over 30 years) there is **no regional database** of patients and their antibodies in the greater New York community.

**ADDENDA** June 9, 2006

10. **A colleague in Port Jefferson, New York** reports that several years ago his hospital contacted the [New York State Department of Health](#) and asked if it would be permissible for the laboratory to inform patients regarding their antibodies, especially if the patients might visit other facilities. He comments that they were told that the **laboratory could NOT directly notify patients of these results**, but that the information needed to be **reported to the patient's physician**. Consequently, the respondent's laboratory instituted a practice where every new antibody identified in their facility was reported to the patient's physician by way of **two reports**. One of the reports was for the **physician's records**. The other report was designed so that the **physician could give it to their patient**, so that the patient could show it to other healthcare providers, if they went to another facility. The respondent acknowledges that in his region there is **no database** of patients who have unexpected red cell antibodies, but he believes that such an 'antibody database' would be a wonderful idea. He acknowledges that **compliance with HIPAA would have to be addressed**.
11. **A colleague in Washington, DC** reports that her hospital has had a system for informing the parents of children who have unexpected antibodies. They request that the **children wear a MediAlert bracelet**. They also place this information into the hospital computer system. She acknowledges that it would be nice to have a national data base system to permit blood banks and transfusion service to know which patients have unexpected red cell antibodies. This is because they have had **several children with red cell antibodies who present at suburban hospitals and get transfused without regard to their antibody status**, despite the issue of the aforementioned letters and request for MediAlert bracelets.

**ADDENDA** June 12, 2006

12. **The transfusion service director at a trauma hospital in Minneapolis** reports that they have been **sending out antibody cards directly to patients along with a cover letter for decades**. Transfusion service physicians have met to discuss trying to establish a central registry, but alas, computer connectivity and HIPAA pose tremendous hurdles. In the meantime, their **blood center reference lab acts as a central repository** for those patients who confirmatory workups are sent to it. This helps immensely when patients with rare or multiple antibodies are admitted to different hospital systems.

**ADDENDA** March 18, 2008

13. **A Transfusion Safety Officer in Canada** reports that **Quebec blood banks share a common computer system for a provincial database of patients' transfusion records.** This provincial database includes records of all patients who have been tested or received blood components or fractionated products since 2003. Historical data was converted into the system at hospitals that were computerized previous to 2003. She adds: "We work very differently in this electronic age and many in Quebec are **debating how standards' requirements regarding historical record check must be applied to this new way of working and the computer system's safety features.** For example: 1) **Users can't help but access the patient's file** where the group and last ABS and other information is evident each time they enter a request, result or product activity. 2) The patients' **special requirements pop up automatically** at pertinent steps such as product selection and distribution. 3) **Historical group comparisons are done automatically** by the system and will not allow a different group to be entered that does not correspond to the previous one etc. Although the system audits and captures these activities **there is no documentation of the record check as was done on paper in the past.** Similarly, we used to document the previous group on the paper requisition to prove the record check and facilitate the comparison to the current one. This is no longer done and even discouraged so as not to bias the tester when entering results. We encourage the user to allow the system to detect discrepancies upon result entry and capture any deviations and problems." The inquiring colleague would like to know **how other computerized hospitals approach the task of historical record checking.**

She continues saying that "Having a provincial database is a **significant advantage** for us, not to mention an **added safety measure** for the patients. Our hospital alone has been able to **detect incidents of "wrong blood in tube"** caught by group discrepancies as well as **histories of antibodies** we would not have known about as they were **no longer detectable.** However, there is a debate concerning historical record check. Now that we have this database, does it automatically become part of the historical record check. Some are asking, **if a blood bank makes an error and then corrects it, are they obligated to let everyone know** that, for example patient X was previously reported as Group O positive, but now corrected to Group A positive.

Please submit comments to the [e-Network Forum](#).

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**Addenda:** Feb. 5, 2003; Apr. 19, 20, 26 & May 5, 2004; Nov. 16 & 20, 2005; June 7, 8, 9 & 12, 2006; Mar. 18, 2008

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