

[National Assembly for Wales](#)

[Health and Social Care Committee](#)

[Access to medical technologies in Wales](#)

Evidence from Dr P Connor & Dr J Kell- MT 7

## **Report to the National Assembly for Wales Health and Social Care Committee**

### **Inquiry into Access to Medical Technologies in Wales: A Case Study on the Difficulties in Commissioning FerriScan**

#### **Background:**

1. Patients with haematological disease (such as leukaemia, bone marrow failure or inherited disorders such as thalassaemia) are unable to make blood cells properly. Failure to make red cells leads to anaemia and the associated symptoms of fatigue, shortness of breath and decreased quality of life.
2. The symptoms of anaemia can be reversed by transfusing red cells (blood transfusion). The benefit of transfusion lasts up to a month and must often be repeated. If a patient lives for several years they will receive scores of transfusions
3. Each bag of blood has an appreciable amount of iron within it as part of the molecule haemoglobin that carries oxygen in the red cell. Humans cannot excrete iron in any normal way. As a consequence, iron accumulates in the tissues over a number of years. This is very toxic and causes damage to several organs including the liver and heart. This damage leads to cirrhosis, heart failure and death.
4. Long-term transfused patients must be treated with specific drugs that bind iron and remove it from the body. This is called chelation therapy. Unfortunately the drugs will also bind to other ions (such as calcium, selenium and zinc) and cause deficiency of these elements.
5. Correct chelation treatment is a balance between removing iron without removing other elements.
6. There are several ways of measuring iron content in the body, and use this as a guide to titrate the dose of the chelation treatment. Many are fairly inaccurate. One technology has emerged as accurate and reliable. This is based on the paramagnetic properties of iron and the fact that a MRI scanner is a very powerful magnet. A MRI scanner can be programmed to use its magnetic field to measure the concentration of iron in a particular volume of tissue, and these figures added together to measure the total iron content within an organ. This is called T2\* scanning

7. This has become the standard of care across the rest of the UK

### **Historical and Current Care:**

8. Until 8 years ago there was only one functioning T2\* scanner in the UK. This was based at the Royal Brompton Hospital in London. There was a similar problem in Western Europe and North America, with very few scanners available in any country. As chelation drugs were developed and were widely used, it became apparent there was a global market to modify existing scanners to allow them to perform T2\* scans and monitor chelation therapy. This modification process has been patented and the company set up based around this (called ResonanceHealth) has dominated the global market. They offer a product called FerriScan. This is a software package that modifies a compatible scanner to be able to perform a T2\* scan. These images/data are securely sent over the internet to Australia where they are processed to measure the iron content of the tissues and a report is sent back to the user. In the UK many of the main teaching hospitals have this technology available (see [http://www.resonancehealth.com/rh\\_findcentre\\_results.jsp?QLocationIdZZEURGBR](http://www.resonancehealth.com/rh_findcentre_results.jsp?QLocationIdZZEURGBR)). The set up process is free and the charge is approximately £250 per scan reported. A patient needs about one to two scans per year.

### **Children in Wales:**

9. Currently there is a small number (<10) of children in Wales who are dependent on transfusion (that is they would die if not given regular transfusions). Most have a potential life expectancy of fifth to sixth decade so it is important to get their care right. They are all seen and cared for in the Paediatric Haematology/Oncology department in the Children's Hospital for Wales based at University Hospital of Wales, Cardiff. Chelation therapy for these children cannot be monitored safely in Wales and they have to travel to Birmingham Children's Hospital (BCH) on a regular basis for scans. This is supervised by Dr Derbyshire at BCH who kindly does not charge us. Some of the children are very young and need to be anaesthetised so that they stay still long enough for the images to be acquired (20 minutes or so). A scanner in Wales would improve their care and prevent long journeys to and from Birmingham

### **Adults in Wales:**

10. There are many more adults who are red cell dependent in Wales (several hundred). They currently have no way of accurately assessing their iron load. Their care is fragmented across different sites (Swansea, Cardiff, Newport etc). Cardiff has the largest clinical Haematology Unit, with a large number of leukaemia patients, but also has the largest number of inherited red cell disorder patients (due to population demographics, as these most frequently occur in black or minority ethnicity populations).

11. Dr Kell (Clinical Director of Haematology and Clinical Immunology, UHW) has been trying for several years to get FerriScan set up in Cardiff but has been met with considerable obstacles. These have included:

Not enough scanning time. The current MRI scanners are at near maximal usage and so there is not enough time to do additional scans

Concerns over compatibility. The conversion process might damage the scanner and there are large costs associated with software or hardware updates.

General inertia

12. The troubles have been endless, to the extent that Dr Connor has not tried to ask for more paediatric general anaesthetic time slots so that the children can be scanned on site.

13. Dr Kell has faced such difficulties at UHW he has approached Velindre to see if they could accommodate a scheme. More scanner time is available at Velindre compared to UHW and Velindre may be able to offer the service following a scanner upgrade.

## **Summary**

Iron overload in transfusion dependent patients can be monitored by a proven technology (FerriScan).

There is a clinical need to monitor these patients in Wales

We believe that this is a good example of a proven medical technology that has not been adopted in Wales

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