

The British Limb Reconstruction Society

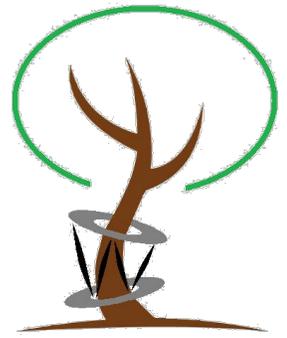
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31 January 2019

Dear BLRS member,

I would like to update people regarding the state of registry information.

Firstly some background. Some years ago there was a Department of Health initiative to gather PROMS [patient related outcome measures], which was passed on to the BOA. They in turn asked the Board of Specialist Societies (BSS) to come up with parameters for measurement of PROMS across our most common conditions or treatments. The NJR has been successful both here in the UK and abroad, and was held up as a model to which we should aspire. Unfortunately, there was no money for this; we were expected to raise funds for it at an individual Specialist Society level.

We were tasked with coming up with four conditions for registries, so the executive committee at the time sat down and brainstormed ideas. We settled on what we considered our three of our most common conditions (pilon fractures, non-unions, and congenital fibular hemimelia in children) as well as a registry of what were then new implants, i.e. self-lengthening intramedullary implants (mainly the Precice Nail).

It took a lot of work, particularly since the conditions were somewhat vague, and crossed borders with other specialties and subspecialties, but we eventually thrashed out the 4 registries, using software that several other specialist societies were using at the time, namely 'Amplitude'.

After due consideration, we decided to start small with only 2 registries, i.e. pilon fractures and the lengthening nail pathway. The only slight hiccup was that the main person for the legality of consent in the UK, Dame Fiona Caldicott, was taking some time to give us definitive information about the exact parameters of the consent process. The NJR had been using a specific consent for some years, but other databases had been decreed to not have valid consent so years of data had to be destroyed!

We went live with Amplitude nearly 2 years ago. We took the decision not to risk entering data until consent rules were cast-iron, which we thought was weeks away and so there were no patients entered initially. Since then GDPR has arrived, lawyers were increasingly involved and a new legal grouping of specialist societies was implemented at the BOA ('TORUS').

The new legally approved consent form eventually came around last August, and we were nearly ready to go when the whole concept of a tie-in with the NJR came up. They work off a completely different software platform, so we would have to extract any data from Amplitude to transfer over.

Additionally, some of us have tried to get the Caldicott Guardians in our hospitals to allow data storage, but without a specific 'pack' for the Caldicott Guardian to sign off, they say we should go back (presumably to Dame Fiona!) and Amplitude can't / won't give us a pack that satisfies our trusts legally.

Long story short, we have been throwing money at Amplitude for some years, and as a tiny society with only about 90 paying members and about 50 associate members we really don't have the resources to keep ploughing forward. We have decided to abandon the project, and have told Amplitude we will not be renewing the contract. Since we don't have any data, we don't need to worry about extracting it at least.

Meanwhile, we do still have a new device, the Precice nail, that I think needs surveillance. As an implant it probably fits well alongside the NJR offering, but their form for feedback relates mainly to existing data and systems, of which we now have none. My plan therefore was to let our membership and Amplitude know that we are dumping the registries project, and when the dust settles maybe revisit it once the NJR is off the ground with central funding with other societies ...

We are continuing to collect performance data at departmental level, and try to collate at national level via the BLRS, but without a company being paid a fortune to provide a registry service.

I implore every member to continue to collect performance data at a local level, and participate in multi-centre trials where possible, but until central government funding is available we cannot afford to maintain a BLRS national registry.

Those of you who have a paediatric practice may note that our experience mirrors that of BSCOS who had similar difficulties trying to get a national registry up and running, and having sat in many BSS meetings I can assure you that many other specialist societies started off enthusiastic with the project but have followed a similar trajectory.

I am happy to receive correspondence / criticism / ideas / requests for further clarification,

Yours faithfully,

A handwritten signature in black ink, appearing to read 'David Goodier', written over a horizontal line.

David Goodier

President, BLRS