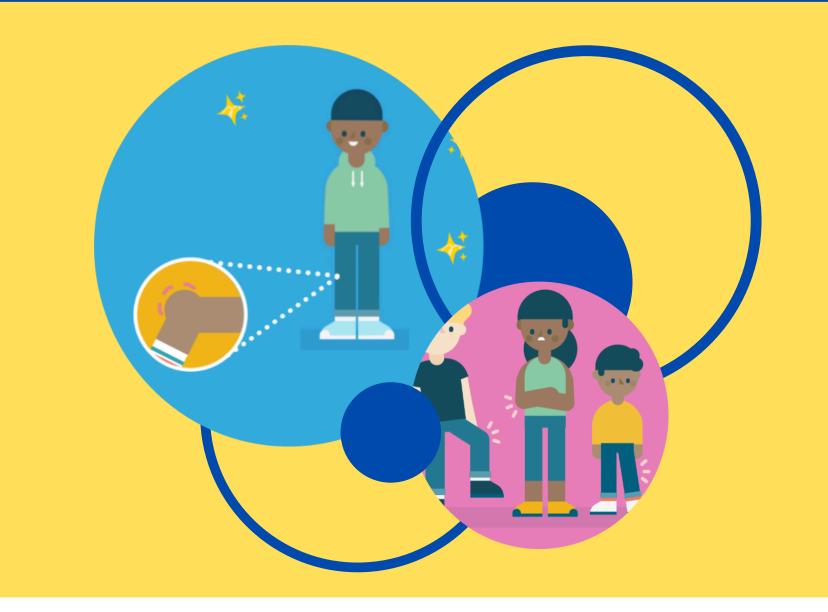
# PIC Bone to the too the top th

## NEWSLETTER



### **66 Message from Tim and Dan:**

We are nearly there and this is very exciting! We are really grateful to all of you for the hard work you have contributed to make PICBone successful. Let's sprint to the finish







line!

## **RETRO RECORDS!**

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No, I'm not asking you to dig out your vinyl copies of 'A Night at The Opera' or 'Clouds', but rather to check that your study site is entering as much relevant data as possible – especially those positive cases which date from before Feb 2020. Every record counts towards the goal of an improved and effective diagnostic pathway. Behind each record there is of course a human story. In my son's case; – it was the timely use of MRI which opened the way to the amazing care he received from surgical and medical teams,

The countdown is on!

We hit two major recruitment milestones this month – we only need to consent **150 more patients** to the Prospective arm of the study and enter **500 more records** to the Retrospective arm to reach our target! Congratulations to all our hardworking sites for reaching these milestones.

#### **STUDY EXTENSION**

Please continue to recruit as normal whilst the funder finalises the decision on the recruitment extension.

and which has ensured that he is now the active; energetic, parentdwarfing, and fridge-devouring Teen that we love.

So let's have those retro-records! They don't just build a better outcome for future patients, but they are also a way of honouring the skills and dedication of the medical, surgical and nursing teams involved in each case following diagnosis.

**Rob Wynford-Harris, PPI Representative** 

#### **STAY IN TOUCH! WITH WHATSAPP**

Keep in touch by joining our WhatsApp Community

Group!

Here you'll receive useful study updates, and we can troubleshoot queries on the go.

# HOSPITAL READMISSION FORMS

This month we've had a lot of queries on what needs recording as a 'readmission'!

We would request that this form is completed when a patient has been readmitted or assessed at a clinic visit and further tests/investigations have been conducted and/or the original diagnosis has changed.

The central team will make your site aware when we have been notified that a patient has been to a different hospital on their 3-month follow-up questionnaire. We would then ask your site to obtain this data from the other hospital as part of clinical governance. Please remember to check your patient's records to see if they have been readmitted to your hospital within the 3-month follow-up window too!

Thank you for your help with this as we really need as much information as possible on the diagnostic pathway and diagnosis for each patient.



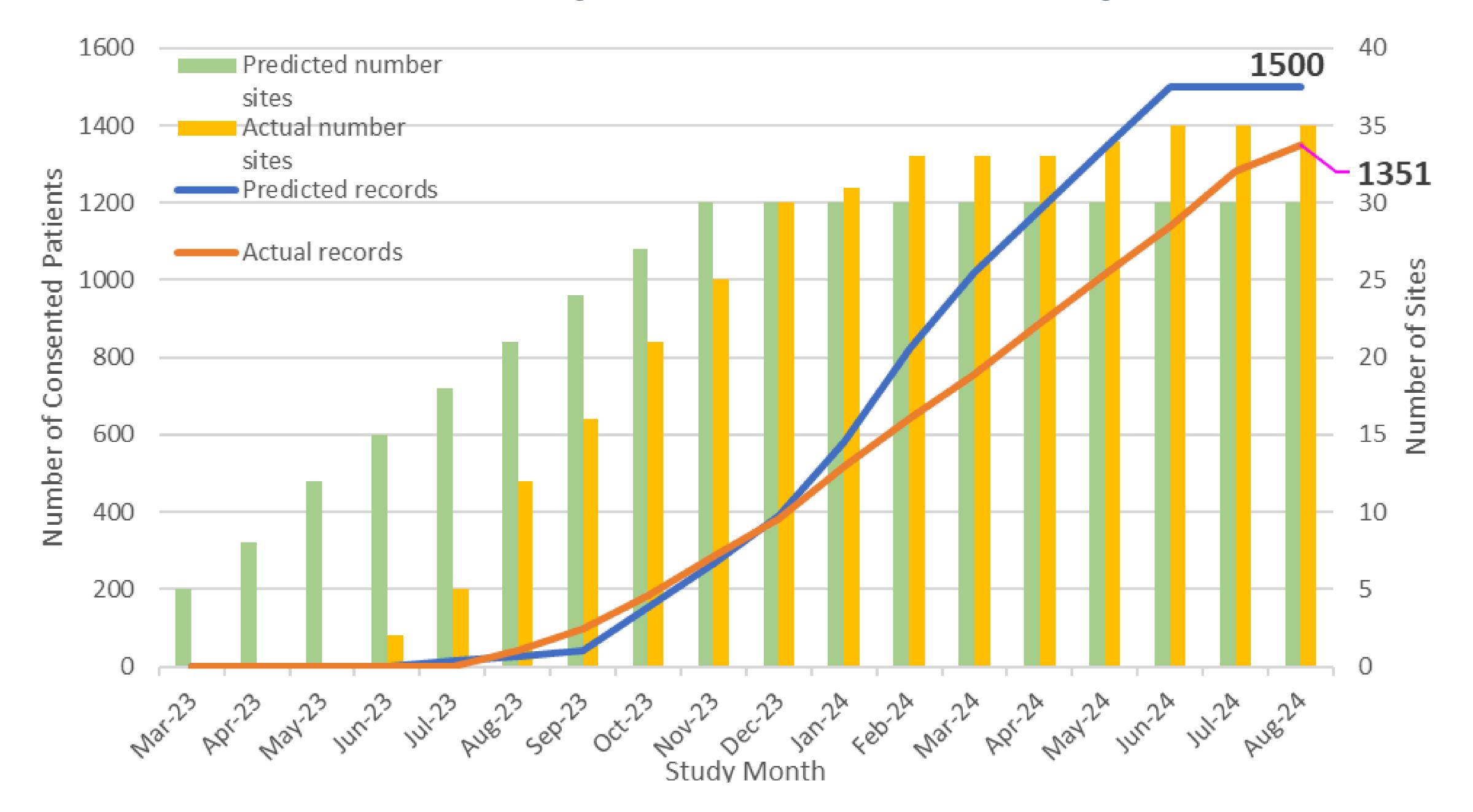


## **3-MONTH FOLLOW-UP QUESTIONNAIRE**

When the central team have been unable to contact a participant for their 3-month follow-up questionnaire, we have been asking sites to provide an alternative phone number and/or try to contact the families for us. We're extremely appreciative of our sites for taking the time to do this. As a result, our follow-up response rate is **over 80%!** These requests should hopefully reduce as participants are now being sent their 3-month follow-up questionnaire by email and/or SMS message.

## **Recruitment Updates - Study Charts:**

#### **Prospective Study Recruitment as of 23 August 2024**



#### **Retrospective Study Recruitment as of 23 August 2024**

