Overnight call to 111 - promised an out of hours call BACK within the hour but non received. GP phone call appointment the next day and face to face appointment later that day ALL missed PIMS-TS which was diagnosed the following day in A&E.

After discharge, I spoke with our GP practice manager who spoke to the GP's there, NOT ONE OF THEM HAD HEARD OF IT! They said they would spread the word out to other practices in our trust.

A local GP surgery, not ours, had never heard of the condition until I put Cai's story on Facebook in December 21. They approached me and thanked me for raising awareness and had seen 3 children that week that presented with similar symptoms to Cai and sent them directly to our local A&E.

Cai was misdiagnosed several times,  mumps, an abscess and infected lymph nodes. PIMS was discussed on the Sunday but he wasn't treated for it until the Tuesday, they continued to treat for infected lymph nodes up until then.

When my son was discharged I was back at the GP’s with his baby sister who had chickenpox. I asked if I needed to worry considering his recent PIMS experience and the GP had no idea about it. I explained and she said “Oh so it’s like Kawasaki Disease?”.

That same GP practice failed to escalate my son when I took him there poorly “it’s just viral”.

Even at our recent check-up the pharmacist in the hospital questioned her aspirin prescription and hadn't heard of PIMS.

Our GP sent us away and dismissed as a viral infection, even though they’d sent us to the ‘hot clinic’ because my son had recently had covid. 111 thought it was a UTI, we didn’t know about PIMS until the doctor taking blood look at all my son’s other symptoms and made the connection. Very grateful they did! Further conversations with our local GP post PIMS have been us telling them what it is, as they had no clue at all.

I’ve been back to Dr’s and A&E twice since January once with my other child and once for myself and spoke about PIMS and both times they didn’t have a clue what I was talking about.

We weren't misdiagnosed but encountered a couple of medical professionals since then who hadn't heard of it - both nurses. One was a nurse I know and the other was a triage nurse at paeds A&E.

2 GPs and an A&E doctor. All 3 had no knowledge of PIMS.

Phone call to GP within last week. Never heard of PIMS. Told me it was a specialist area and to contact consultant. A doctor in local hospital diagnosed my son with a UTI, took him to different hospital next day, urine screened twice no infection. Thankfully the doctors/paediatrician in that hospital knew of/had treated between 50-60 kids within last 2 years for PIMS, got a diagnosis within a few hours.

Dismissed 6 times by various doctors, A&E, out of hours doctor, 111, told to manage with paracetamol & not listened too.

Eventually sent to a child’s hospital ward by another GP who thankfully agreed to see my daughter that day, who was convinced it was appendicitis.. was finally in the right place, they had also had a case of PIMs the previous week & thankfully same doctor recognised it at the hospital. Day 6 of the worst worry/illness, was completely harrowing. It’s so scary knowing these kids’ lives can be down to luck.

At A&E.. my son with many symptoms for PIMS alongside serious concern for Meningitis was sent home day three of unrelenting high temperature. Three days waiting for the gastroenteritis the doc had diagnosed to pass to us or subside at least.. GP sent us to Hospital Paediatrics as wasn't sure what was wrong. Thankfully the right thing to do! Saw her after being discharged.. she hadn't heard of it before!

When arranging an aspirin prescription with the GP over the phone, the GP hadn't heard of it and didn't have a code in their system to put against the prescription (as it was unknown to the practice).

After a discharge from the hospital had a chat with my GP who never heard of PIMS-TS previously. That was towards the end of 2020 (a year into pandemic).

We had a misdiagnosis of tonsillitis by GP at the hospital through a 111 call. Then misdiagnosed a day and a half later as having an allergic reaction to antibiotics due to the rash that appeared. When we went back for a third time they thought strep A or glandular fever but did also mention PIMS.

Went to the doctor recently and the GP had never heard of PIMS and we had to explain it to him.

My friend had a “What is PIMS” when she queried it post appendectomy five weeks post Covid for her son… From the paediatric surgeon who had operated.

This was November 2021. I could not believe they’d not heard of it or considered it prior to operating… Fortunately he recovered and inflammation was just his appendix, but with that timeline it should have been considered. And 19 months into a pandemic a serious complication of Covid should be known about by all frontline staff

1 GP, twice111 CALLS, Twice A&E, none of them knew. They said tonsillitis, allergy to penicillin and then scarlet fever.

We got misdiagnosed with appendicitis (this brought us into hospital), then suspected bacterial intestinal infection, sepsis. I believe it helped that I asked on several occasions in the hospital if it could be PIMS - it kept them thinking. After 3 days PIMS was considered as heart condition worsened, thus immediate transfer to larger hospital and into intensive care unit. Upon discharge I contacted the paediatrician, who didn't know what PIMS was...

My GP did not know what PIMS was. She dealt with my son and was obviously very concerned about him but seemed puzzled and sent us away after 2 visits saying it must be viral but if symptoms got worse to call 111 (it was a Friday). 111 told us to go to A&E immediately on Saturday once I'd mentioned he had covid 3 weeks earlier. A&E treated him immediately.

The surgery has since apologised and done training so all their GPs now know what it is and what to look out for. x

GP no idea what it was! Hosp paediatric consultants at the time the same! Both my children missed PIMS!! Now suffer PANS and long covid 2yrs on. I'm positive the PANS and the fact they are always ill ALL the time now is because they did not receive timely treatment when they should have realised it was PIMS. Ignored me telling them it's this!
P.S. my boys had an unrelenting high temperature for 3wks each and even though I told them this and said it's PIMS, they couldn't wait to get us out of there! I begged at an appointment and broke down. She said "it is the trauma for them, it takes time to heal", when I said "but they are still ill!" long after the acute infection.

It was when IV antibiotics didn't work and CRP levels increased that steroids were administered for PIMS. I've spoken to several friends who are medical professionals since (NP's, GP's, and a cardiac nurse) and none had heard of PIMS.

We would like to put forward some suggestions to improve matters, from the patient's viewpoint and work with you on this matter. I will prepare these and send over shortly. In the meantime, we would be interested to know how and when the RCPCH protocols for PIMS were shared with GPs and whether that information has actually reached all of them and more generally, how 'diagnosis' rates are monitored at GP level.