

Leg Pains, Headaches and a Single Ventricle Heart

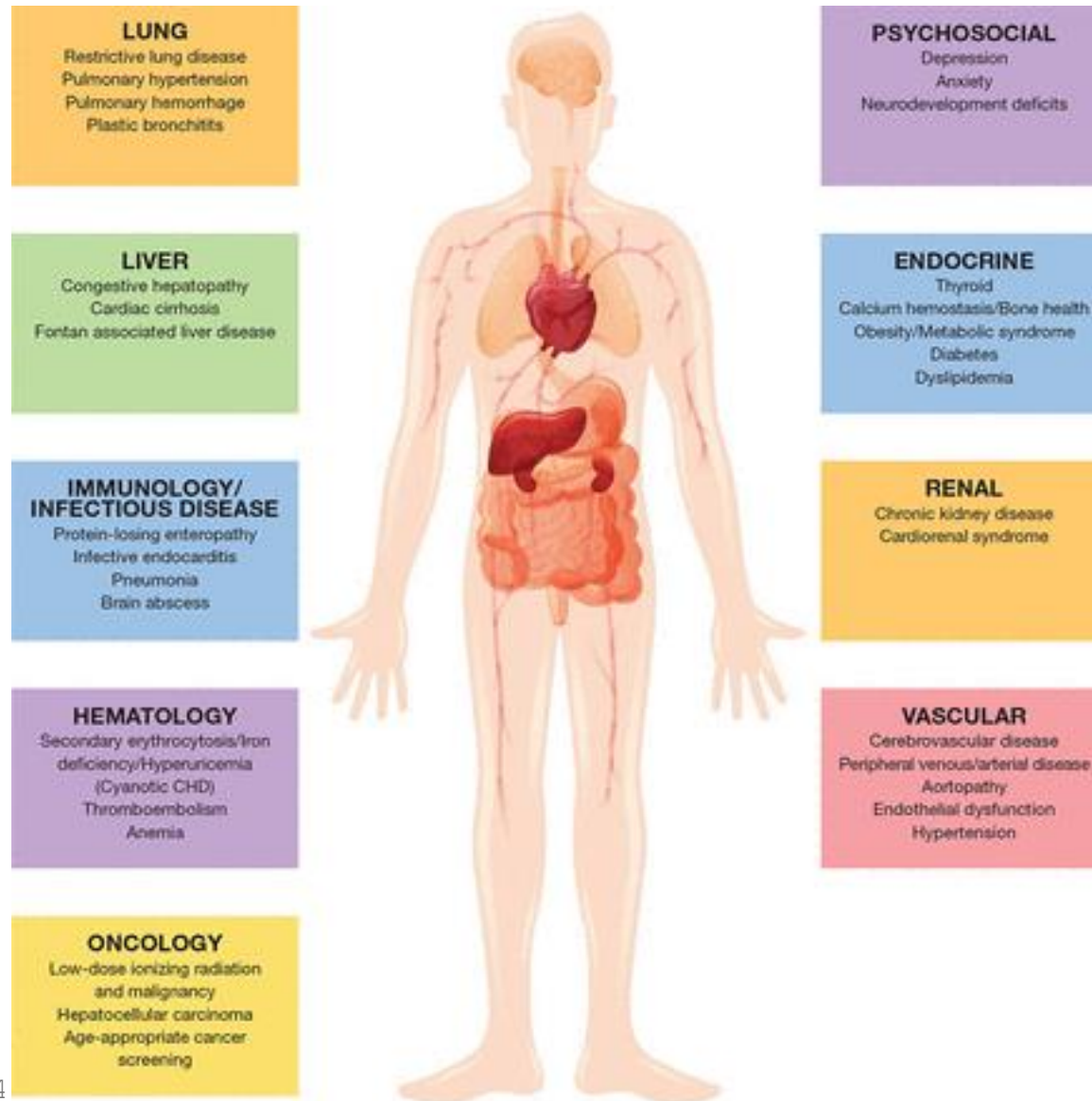
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Complications of SV/Fontan



'My 17-year old son has been complaining of leg pain for years. Just last month, we spoke to his cardiologist who couldn't identify with it from a heart perspective.'

Morbidity (how patients feel)

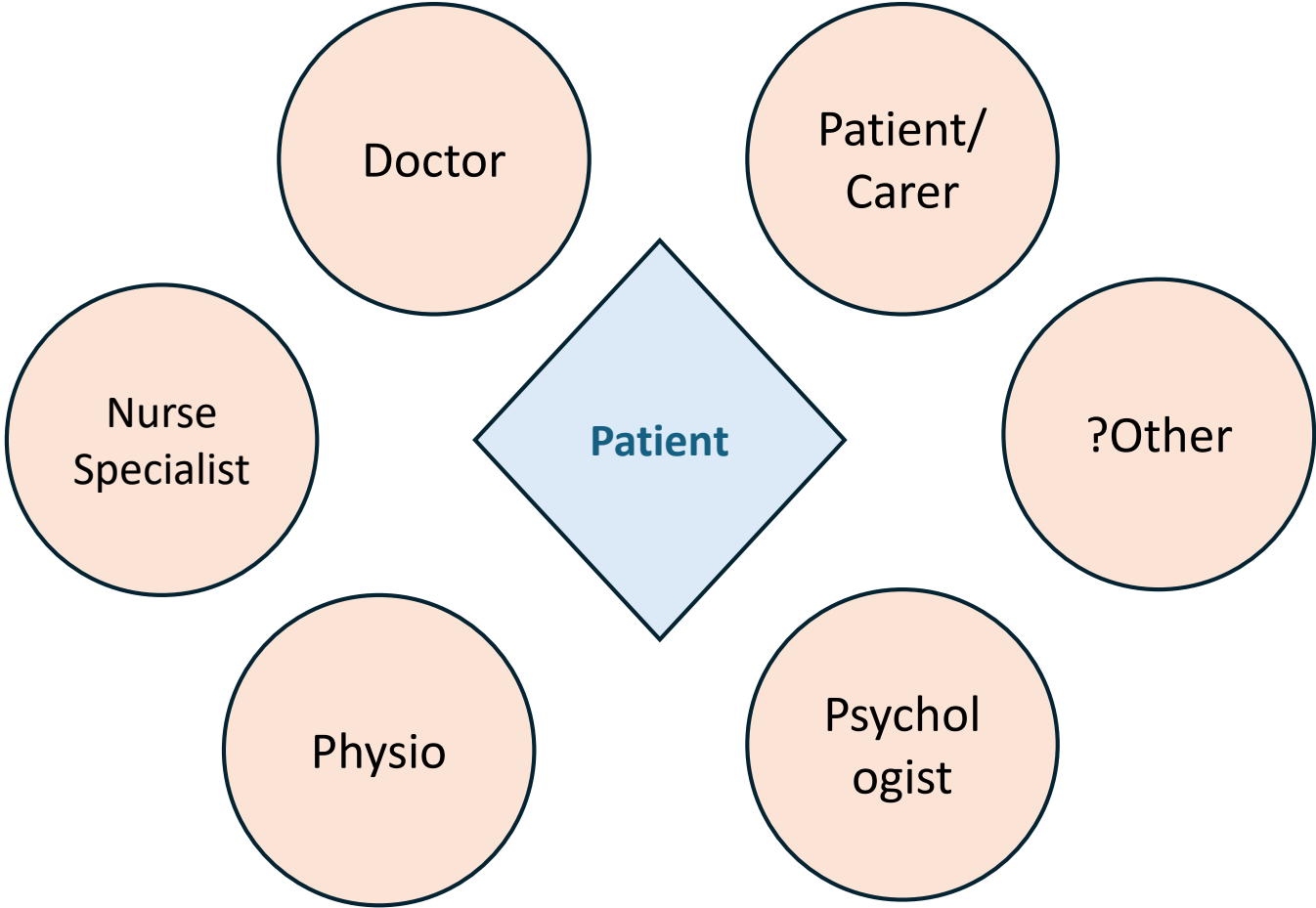
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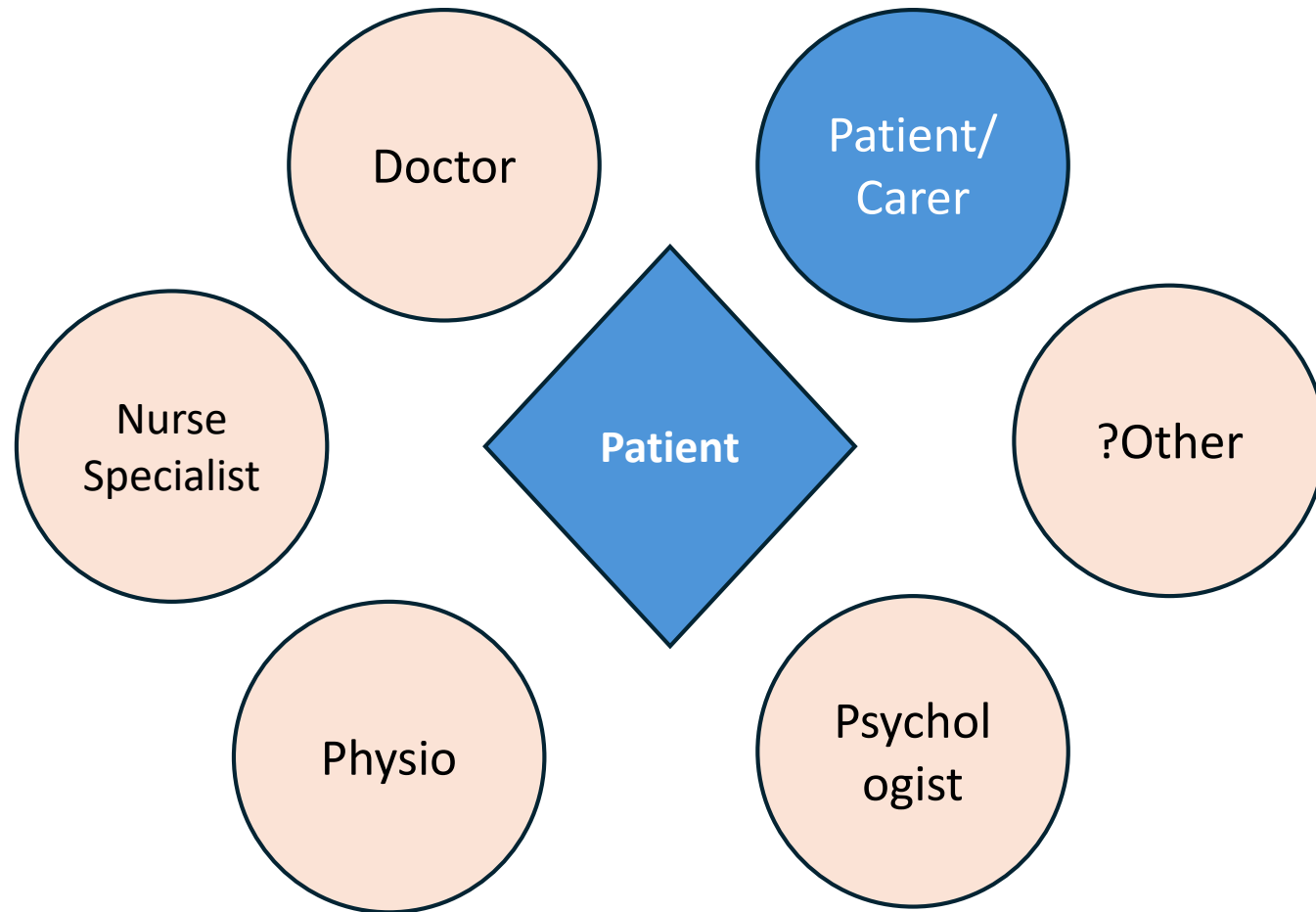
Changes clinician relationship

Peer support - sharing solutions



Identifies new areas for QIP/research







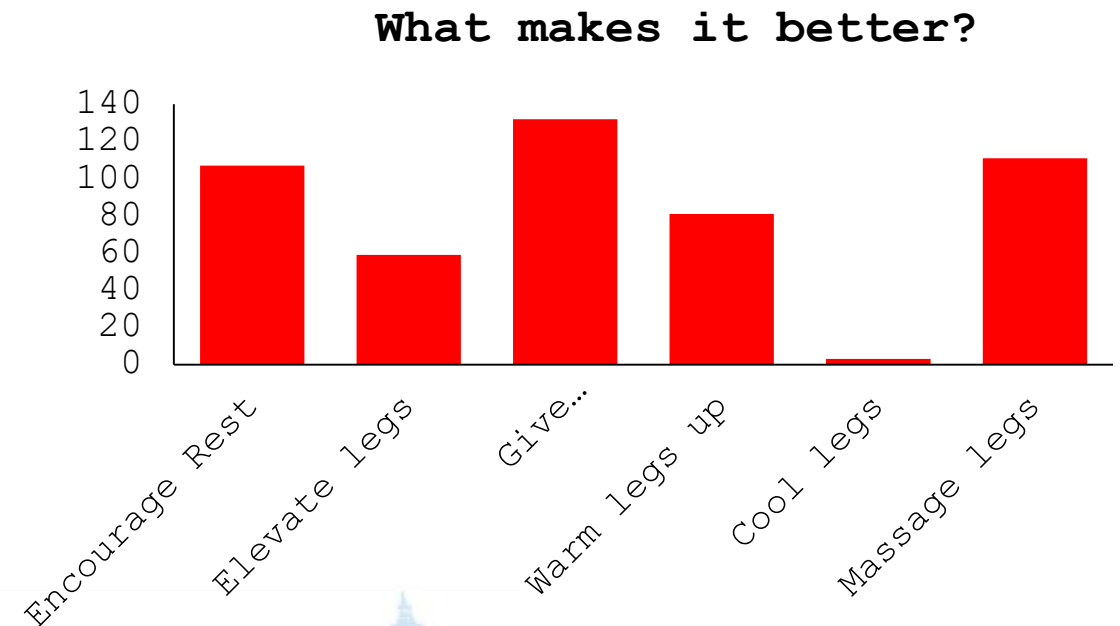
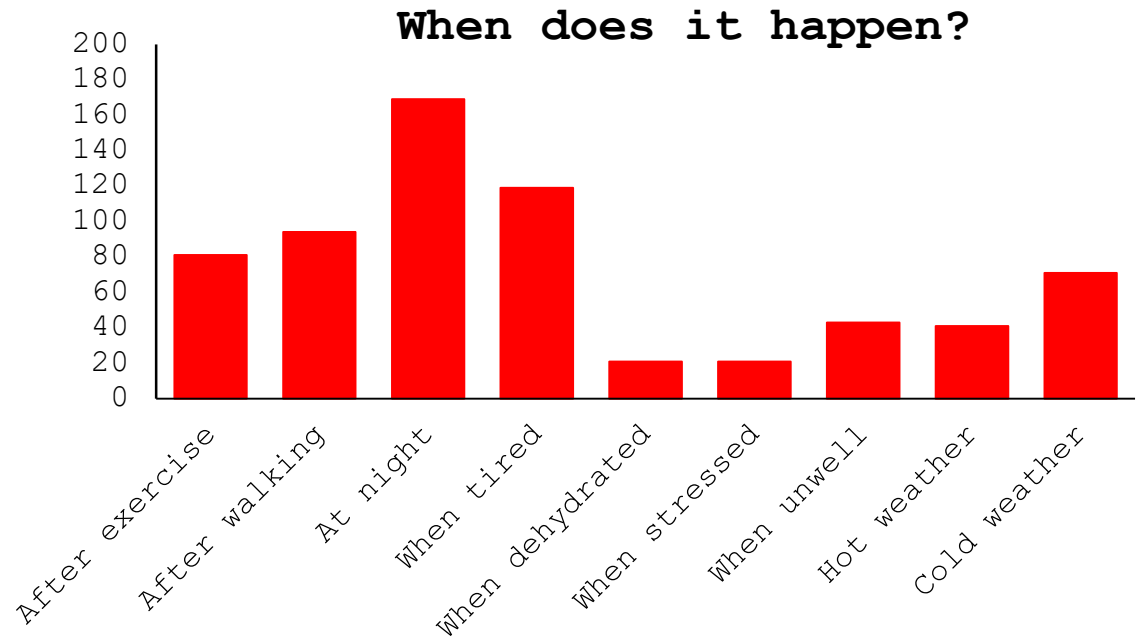
Survey sent out by LHM

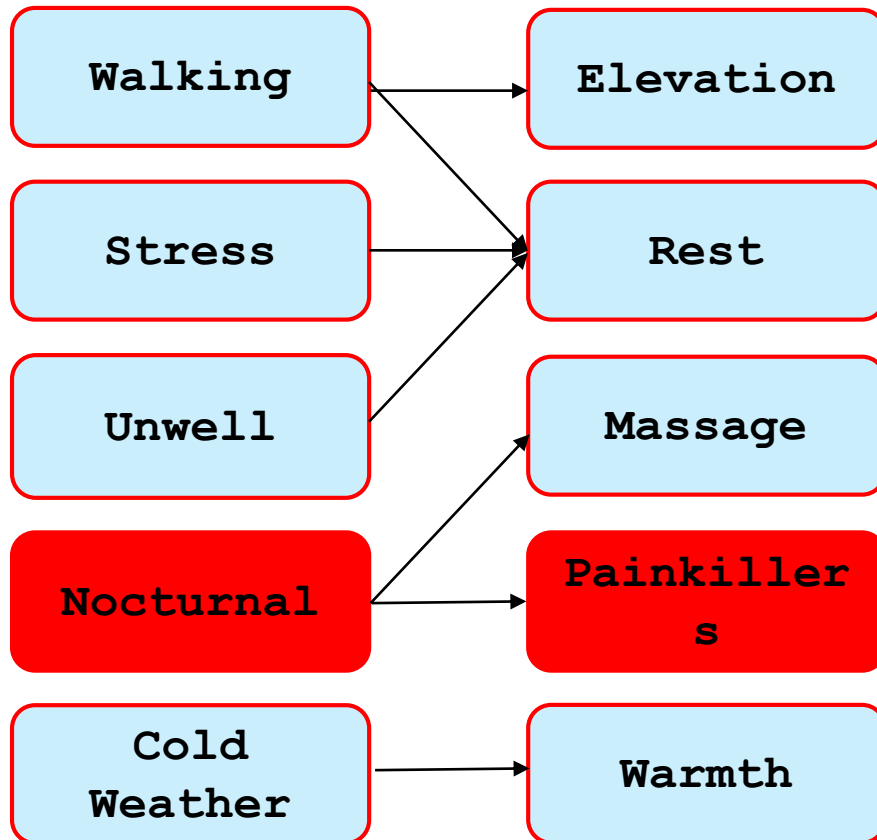
220 respondents

- 57% male, age 8.3 years [0.2-29], 69.5% SV

93% reported leg pains (likely selection bias)

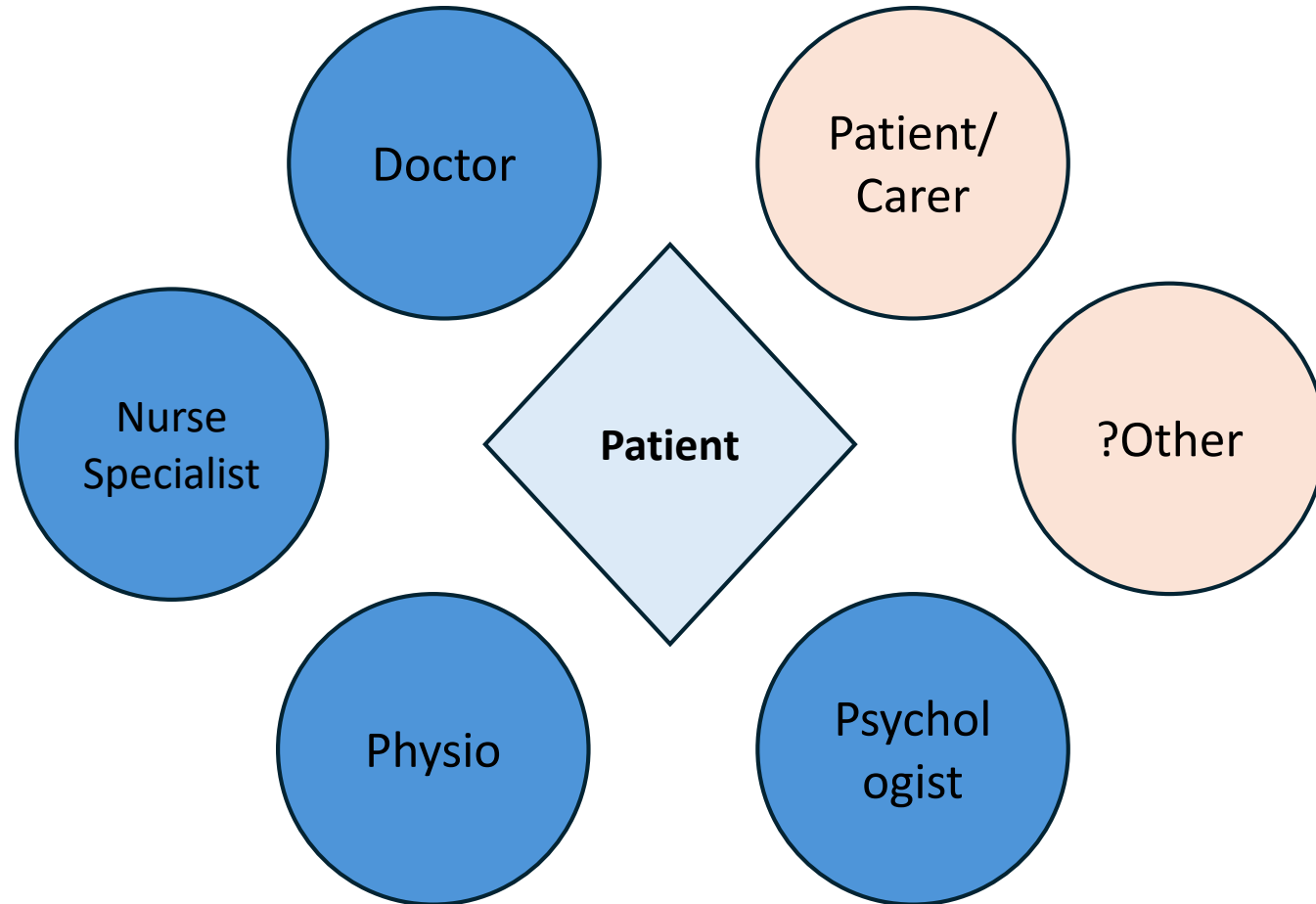
3 times more frequent than healthy siblings





- Not influenced by gender
- Associated with stress in older respondents
- Significant association with aspirin ($p=0.01$)
- Universal in those who were hypermobile ($n=12$)



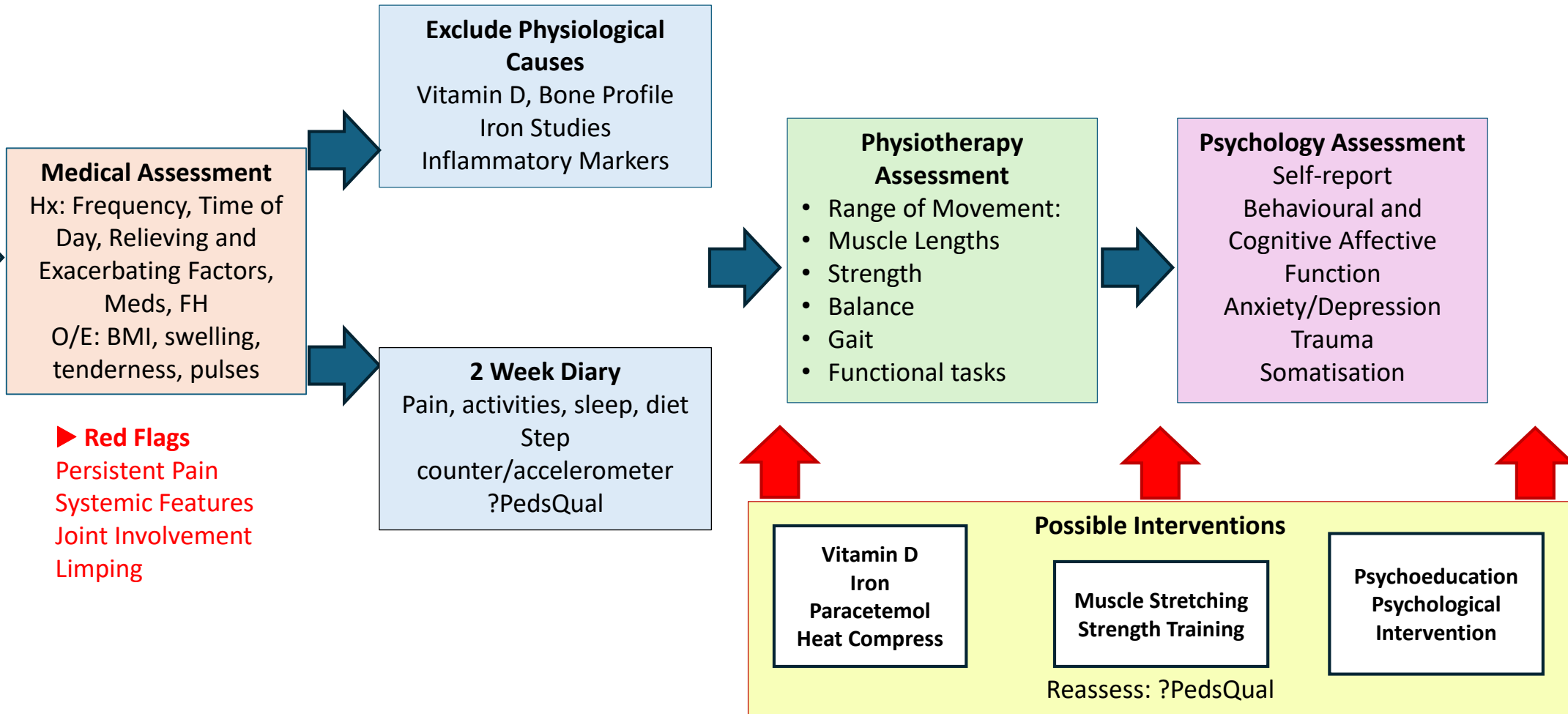
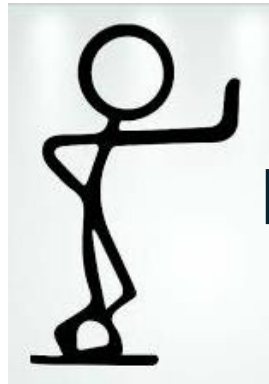


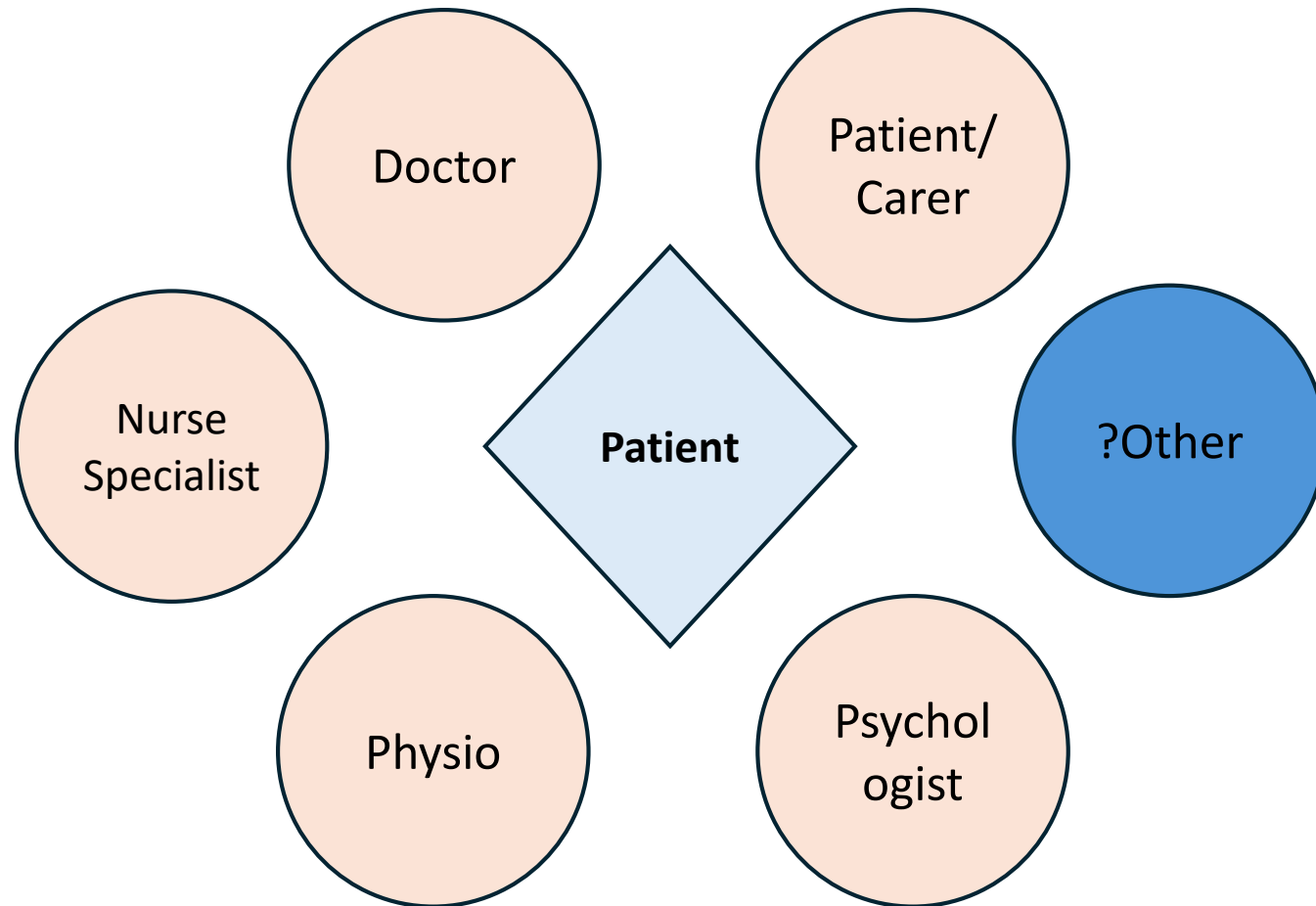
The key finding for these children tends to be muscle weakness particularly around the gluts and, hips and core which then alters the biomechanics of the lower limb which can then cause pain. The pain tends to be worse at night due to little distraction and the tired muscles at the end of the day.

Strengthening programme and some targeted exercises has been shown to improved symptoms.

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Clinical Pathway Development





Headaches

? 50% Fontan patients [Pike et al. 2011]

? Elevated dural venous sinus pressure

? Infection/abscess



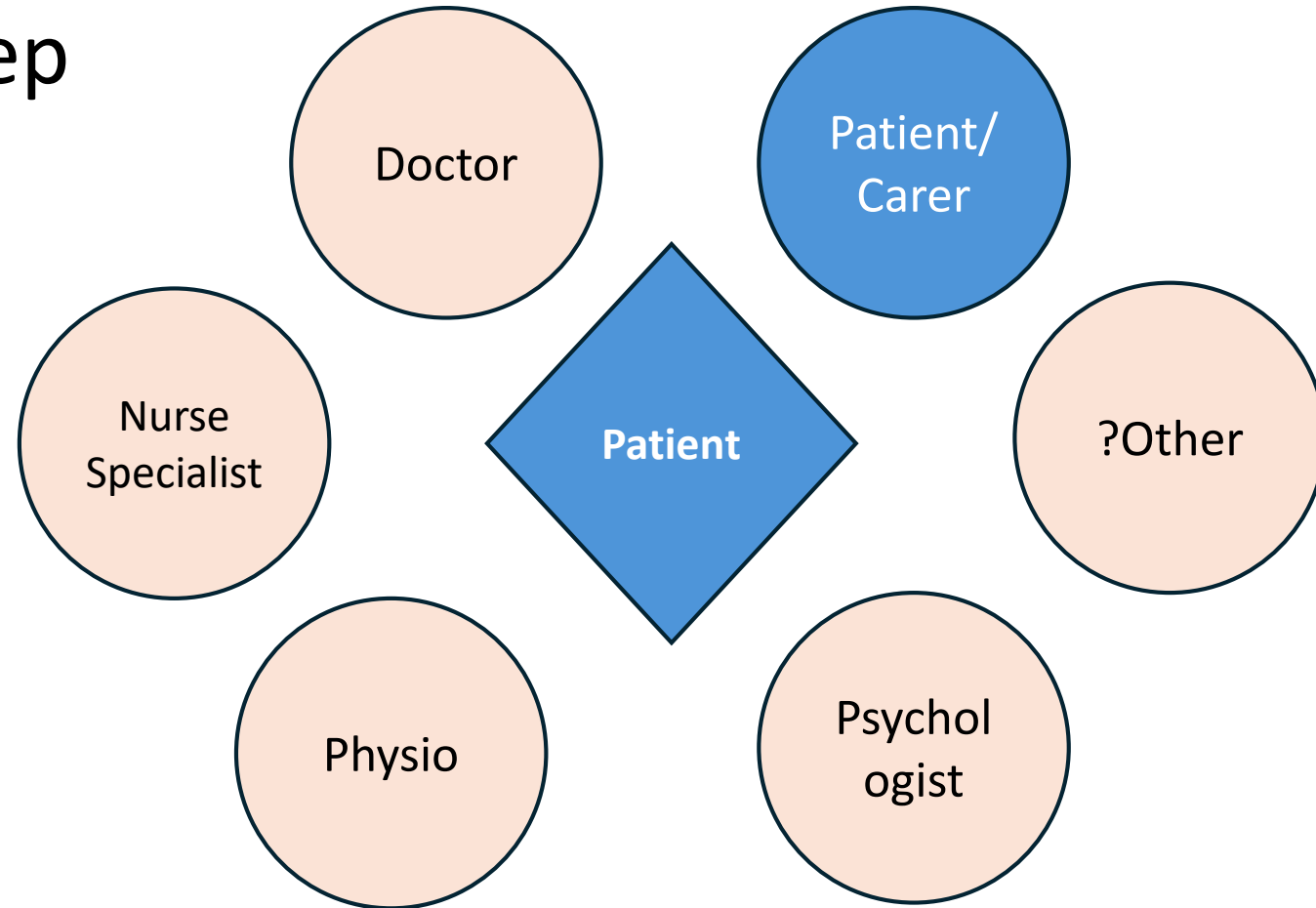
? Medication

? Right to Left Shunt, like PFO

? Shunt closure/Aspirin



? Next Step



To Conclude

- Social media facilitates important evidence for what matters
- Patient groups & organizations can help delve deeper
- The MDT perspective can shape a pathway forwards
- Regular audit and evidence review will refine the approach

