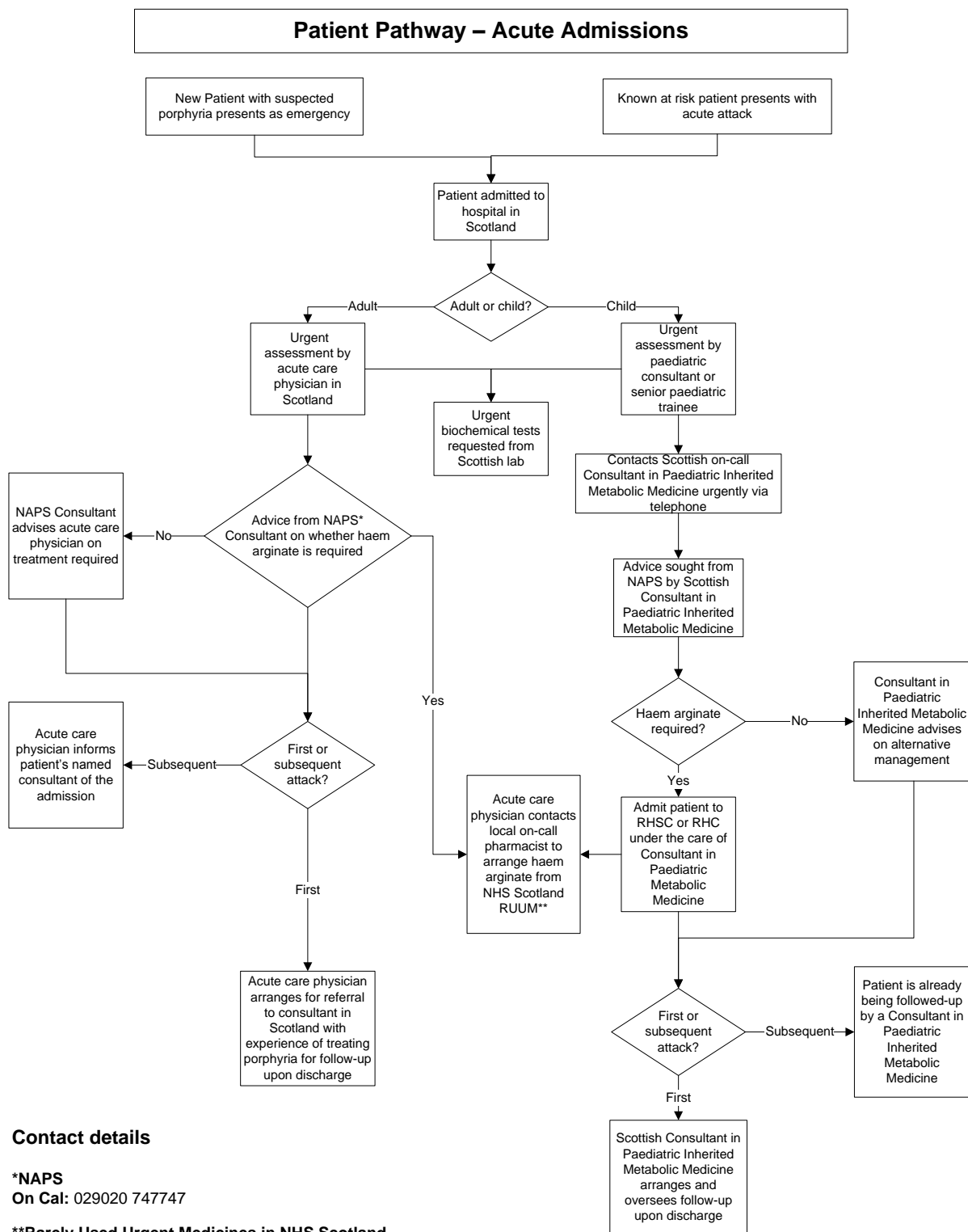


ACUTE INTERMITTENT PORPHYRIA NATIONAL SERVICE SPECIFICATION



Contact details

*NAPS

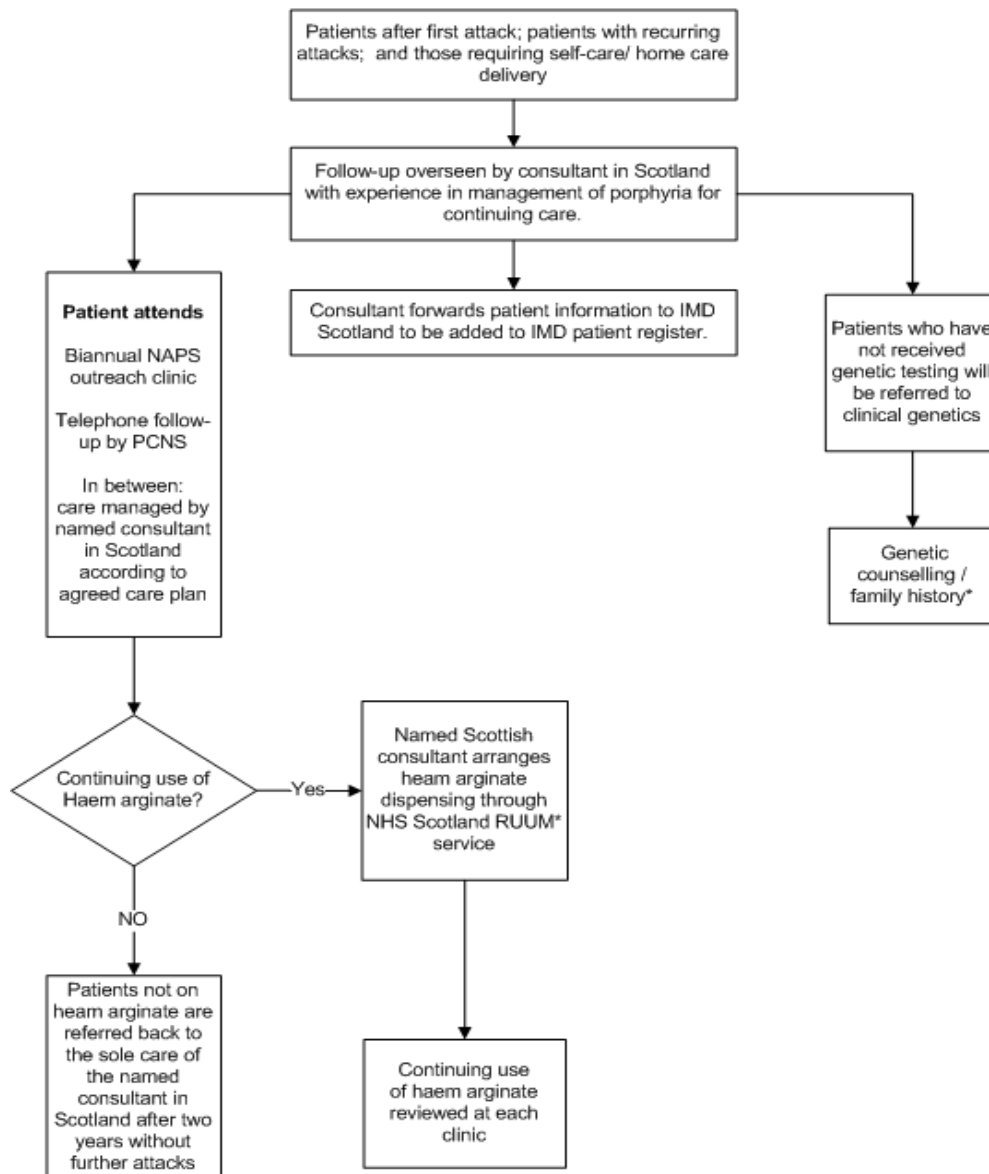
On Cal: 029020 747747

**Rarely Used Urgent Medicines in NHS Scotland

Normal working hours : 0141 452 2975

Out of hours : On call pharmacist via hospital switchboard – 0141 201 1100
(haem arginate is held at Queen Elizabeth University Hospital in Glasgow)

Patient Pathway - Follow-up care



* Asymptomatic patients with AIP mutation identified through family screening should be referred to a consultant in Scotland with experience of treating patients with porphyria for decisions on case management and follow-up as required. The consultant forwards patient information to IMD Scotland to be added to IMD patient register.

This guideline is not intended to be construed or to serve as a standard of care. Standards of care are determined on the basis of all clinical data available for an individual case and are subject to change as scientific knowledge and technology advance and patterns of care evolve. Adherence to guideline recommendations will not ensure a successful outcome in every case, nor should they be construed as including all proper methods of care or excluding other acceptable methods of care aimed at the same results. The ultimate judgement must be made by the appropriate healthcare professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan. This judgement should only be arrived at following discussion of the options with the patient, covering the diagnostic and treatment choices available. It is advised, however, that significant departures from the national guideline or any local guidelines derived from it should be fully documented in the patient's case notes at the time the relevant decision is taken.