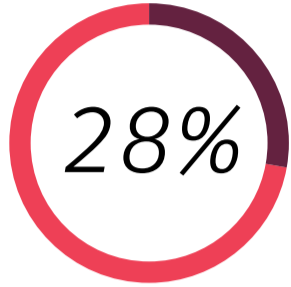


# Kawasaki Disease is the leading cause of acquired heart disease in children in the UK

## 2016 Outcomes



of treated children with adverse cardiac impacts



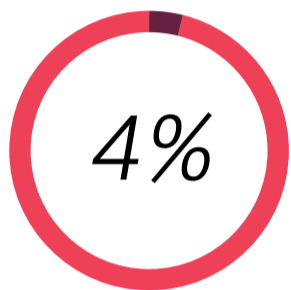
-day median treatment

**Inconsistent**  
application of care protocols



**Partial UK coordination**  
knowledge pockets, poor general awareness

## 2020 Outcomes



(or less) of treated children with adverse cardiac impacts



-day median treatment

**Consistent**  
application of best practice care protocols



**Entire UK coordination**  
high level awareness, strong partnerships

### General Awareness

### Diagnosis

### Acute Phase Treatment

### Clinical Supervision

**What is needed?**

Establishment of "common knowledge" around Kawasaki Disease across all communities  
Embedded multi-disciplinary, cross spectrum medical awareness  
Readily available, U.K. specific information on Kawasaki Disease, multiple formats for range of audiences (medical and lay)

**What is needed?**

High parent awareness levels  
Primary care knowledge embedded  
Knowledge embedded in Secondary care (both A&E and paediatric training grades)  
Paediatric cardiology knowledge embedded  
Protocols in place and nationally adopted for diagnosis and immediate treatment requirements

**What is needed?**

Protocols in place and nationally adopted for treatment  
Protocols in place and nationally adopted for clinical surveillance / monitoring of impacts (full range not narrow)  
Established UK evidence base from which to derive (practice based) UK specific policy and action  
Knowledge embedded in secondary care (A&E, paediatrics and paediatric cardiology)  
Multi-disciplinary team participation and knowledge (cardiology, infectious disease, rheumatology)  
Readily available best practice treatment options, based on best available evidence

**What is needed?**

Protocols in place for ongoing supervision and nationally adopted  
Protocols in place for significant events – both protocols regularly reviewed and adjusted to respond to emerging research evidence (required)  
Paediatric cardiologist / A&E team knowledge embedded  
Multi-disciplinary team engagement and knowledge (cardiology, infectious disease, rheumatology, dermatology, psychology) – resourced and enabled.  
Continuity from paediatric cardiology to adult cardiology services  
Timely, detailed information transfer from Secondary to Primary care.  
Rapid pathway back to secondary care if GP/parental concerns.

**What is in place?**

Negligible public awareness  
Poor Primary care / A&E awareness  
Awareness in paediatric training grades assumed but unconfirmed  
Limited medical knowledge in specialist groups / knowledge "pockets"  
Sparse technical information is poorly accessible, often out of date  
Narrative (inc NHS online) still refers to "rare" and connects to US data

**What is in place?**

Negligible parent awareness  
No diagnostic protocols  
Limited medical knowledge vested in specialist interest groups and knowledge "pockets", unequally distributed  
Inconsistent initial treatment  
Incomplete evidence base for UK presentation / diagnosis

**What is in place?**

No established treatment protocols  
Very limited knowledge in specialist localised groups  
Lack of formal co-ordination of specialists except where leading hospitals recognise and advocate an integrated approach (not resourced)  
Inconsistent acute treatment approaches  
Incomplete evidence base for UK acute treatments

**What is in place?**

No nationally recognised protocols  
Inconsistency of aftercare/management  
2013 Guidelines – not widely adopted  
NHS London cardiovascular management guidelines 09/15 – not widely adopted  
NHS Alert –Kawasaki Disease 11/05/16  
European guidance is pending; not in place  
Knowledge vested in specialist groups  
Absent UK evidence base for long term care and management

*...it's time we changed that*

