

CHILDREN'S RIGHTS, PRIVACY & SOCIETI ORIGINATED CONTENT

Last Reviewed – January 2021

Next Formal Review Date – January 2024

Our work

Together with many dedicated Societi Supporters, we undertake to raise funds and secure grants so we can in turn raise awareness, improve clinical supervision of children affected by Kawasaki Disease, enable much needed research and support KSSG, the UK support Group. The scope of our work is very broad and the scale of our reach and therein the size of our organisation, is growing all the time.

Our aims & policy intent

Societi Foundation sets high standards of delivery for all our work and we continually work to provide high quality services which meet the needs of the families, patients and clinicians who access the resources and information provided by Societi.

From the outset, Societi has taken a clearly demonstrated position with regard to the use of direct child patient images in our awareness raising and wider work. **We do not use these** - we will not use images of children in any Societi originated material. This policy statement provides the context for this.

Context

Kawasaki Disease may be described as an enigmatic disease. Whilst there are "typical" clinical symptoms which can be identified, unlike many childhood diseases there is little which is truly characteristic of a Kawasaki Disease clinical presentation; this being one of the pernicious aspects of the disease which has led it to be under-diagnosed and misdiagnosed over time.

Kawasaki Disease - the disease is not "characteristic" in clinical presentation

Kawasaki Disease symptoms present differently in children of different ages and backgrounds. As such, it might be concluded that one of the reasons Kawasaki Disease has been under diagnosed in the U.K. over time could be because clinicians have looked for specific visual clues, and ignored possible Kawasaki Disease diagnosis when an image or feature they recall from a single patient image prompt is absent. We have many parent experiences of this to draw on.

Addressing this problem identified from patient experience, we developed a series of six "Symptom icons", (icons) informed by dialogue with our Scientific Advisory Board Professor, Prof Tulloh, to ensure appropriate representation and use of language in our description of the main Kawasaki Disease clinical symptoms.



Persistent fever



Cracked lips/
strawberry tongue



Rash



Swollen glands



Swollen
fingers/toes



Bloodshot eyes



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The icons, which are always presented starting with or emphasising most, the icon for persistent fever, encourages learnt understanding of the disease symptoms as a cluster, without reliance on visual "clues" from one-off images which we know are not properly representative of the vast range of potential presentations of Kawasaki Disease symptoms across unique children. Our core aim in developing the icons therefore is that the SYMPTOMS CLUSTER rather than a "picture" of one child's clinical presentation of Kawasaki Disease becomes the learnt aid to better, earlier diagnosis.

Kawasaki Disease and long-term privacy rights

The icons also remove the need for use of images of ill children showing symptoms who - whilst parental consent can be properly and legally sought - are children at their most vulnerable. These children, where images are used, are also themselves today unwitting participants in global, often unbounded and indelible multi-platform social media activity, an area in which the law with regard to the rights of individuals and their protection is actively evolving.

This evolution of legislation which is occurring globally, considers the rights of children whose privacy and wider human rights may be unintentionally compromised by the prior consent of parents to public sharing of images, direct data and implied data - which may be indelibly shared (for instance through social media). Should this sharing not be consented by the child, once into adulthood, the retrieval of personal images, health status data and other associated information may not be possible. In fact it is very unlikely that full retrieval would be possible.

Kawasaki Disease - Unquantified long-term outcomes

As a disease where there is much still to learn, the long-term prognosis and health implications for children and young people affected by Kawasaki Disease are currently unclear - as with many aspects of Kawasaki Disease. Recent UK research indicates longevity of disease action as well as greater lifetime risks than previously understood (even five years ago). It may be that parental consent for the use of children's images is given based on supporting awareness raising and the fight against Kawasaki Disease, on the premise that their child has less ongoing health vulnerabilities than have been or are yet to be identified.

This poses challenges for both parents and children - in terms of children's rights and their data protection and potentially also in relationships between parents, children, and their healthcare providers.

Extent of use of Icons

Whilst use of the icons conveys powerfully the cluster of key Kawasaki Disease symptoms and is a strong tool in the education of both clinicians and parents, they cannot in isolation convey *the child* who is the majority patient in cases of



Kawasaki Disease (over 70% of cases in the UK are in children under the age of 5).

We therefore recognised the need to augment the use of these (as indeed patient images if used would need to be augmented) with additional graphics to convey key facts. Some examples are included below.

Kawasaki Disease

#1 cause of
acquired
heart disease
in children



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Developing Societi 100

Having taken the position as an organisation that we will not use images of children in Societi originated material, noting privacy rights and other children's rights can be quickly compromised, we understand fully the need for high impact visuals which can reach our intended audiences well.

In mitigating the known risks and balancing these with the absolute need to convey the essence of *child* and children affected by Kawasaki Disease, we have worked with a junior artist to develop Societi 100, a drawn series of well over 100 children. Wherever possible we will use these drawings as part of our brand evolution, where appropriate together with icons and other graphics, to convey the "child" affected by Kawasaki Disease.

Examples of Societi 100



Societi Brand Guideline - Icons and Societi 100

Further information on the use of our icons and Societi 100 is given in the Societi brand guideline.

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