Children's Liver Disease Foundation Submission to NICE

Virtual Touch Quantification to diagnose and monitor liver fibrosis

The use of technology which can *effectively* support the diagnosis and/or ongoing management of children affected by any type of liver disease in childhood, and limits the number of liver biopsies required by children, is supported by the charity.

We know that the use of Virtual Touch Quantification is quick, doesn't require a hospital stay or anaesthetic, is non- invasive, has no recovery period and requires far less staff resources to undertake

We cannot comment on the efficacy of the technology as a tool to manage/ monitor the conditions. In this submission we have reflected on the experiences of children (and their families) where biopsy is an ongoing feature of their journey with liver disease

1. **Information about any aspects of current management of liver fibrosis which might be improved by patients, service users or carers having access to Virtual Touch Quantification.**

   Many of our children have to face multiple liver biopsies in order to diagnose and monitor their condition.

   Biopsies in children are undertaken under **general anaesthetic** which comes with it's own well documented risks. Children are required not to eat or drink prior to the procedure, being subject to the anaesthetic and medicalised invasive procedure can be very stressful for the child and family alike. On coming round after the anaesthetic side-affects can include headaches, sore throats feeling dizzy and sick, vomiting and being upset. Parents report concern about possible adverse reactions to anaesthetic and their child's experience of being anaesthetised. This can affect the child's experience of treatment for their condition and approach to future hospital visits and care. - **The use of Virtual Touch Quantification could reduce the total number of anaesthetised procedures that children are required to face as part of their care.**

   Biopsies are an **invasive procedure** and can cause significant discomfort for the child in the hours and days following the procedure. Pain relief is often administered, dressings applied and bed rest required. This is difficult for children and parent/ carers alike. Parents are asked to consider the risks of the procedure amongst which can be the small but significant risk of bleeding. These risks continue past the immediate 24hr recovery stage. This means that even when the child is free to return home, close observation is needed and signs of possible infection watched for. Children are required to avoid contact sports, which means time away from 'normal life activities' (and potentially friends) for a period of six to eight weeks. This can have an effect on the children, heightening feelings of isolation .These concerns all add to the worries of parents. Where alternative non- invasive procedures can be used, they should be used.

   Most biopsies in children require an overnight stay in hospital**.** The need for an overnight stay can have a variety of often unconsidered ramifications for the child and wider family. Often the parent will be required to take extended time off work, costs of accommodation, food, travel, car parking etc. mount up and add financial burdens in addition to those relating to medical aspects of the intervention. The child has to have extended time away from school Time away from home also has implications for other members of the family who are left at home. Siblings are often affected by the

overnight stays, being without parent/s, these issues if experienced often can sometimes make them feel isolated and 'less important' within the family. **The use of Virtual Touch Quantification could reduce the number of times children/ families are required to stay in hospital overnight as part of their care.**

- Fear – with different ages the reaction to the knowledge of needing a biopsy will differ, preparation by parent/carer to explain the situation and manage emotions of child and their own concerns

- Impact on development – missing time from school and social situations for patient could have long term impact