

## CONSERVATIVE CARE IN PAEDIATRIC END-STAGE KIDNEY DISEASE

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### Abstract

Chronic kidney disease describes damaged kidneys. In 'end-stage kidney disease' (ESKD), kidneys don't work as they are supposed to or have stopped working altogether. This is not survivable without treatments known as renal replacement therapy (RRT). RRT includes dialysis (blood cleaning) or kidney transplantation.

While RRT offers a chance of survival, it is not a cure and can fail. Reaching ESKD early in life means children depend on RRT their whole lives. This can be burdensome and, in some cases, difficult to perform due to patient size or other medical problems. For some children, it may be in their best interests not to start RRT and to instead offer conservative care. Conservative care is a term used to describe treatment of a child's kidney disease without RRT. It includes managing symptoms or complications of their kidney condition. It may also include end-of-life care.

This study aims to identify children with ESKD who receive conservative care. We wish to understand how the decision not to start RRT is made and important factors that are weighed-up. Running this study through the BPSU will mean affected children, who may be under general or specialist paediatricians, can be recognised. It is hoped that findings from this study will help to inform children and families about treatment options for ESKD. It will also help professionals to provide equal access to high-quality care for affected children and families.

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### Website

[www.rcpch.ac.uk/bpsu/ESKD](http://www.rcpch.ac.uk/bpsu/ESKD)

### Background

Chronic kidney disease (CKD) describes damaged kidneys. In 'end-stage kidney disease' (ESKD), kidneys no longer work as they are supposed to or have stopped working altogether. This is not survivable without renal replacement therapy (RRT). RRT includes treatments such as dialysis (blood cleaning) or kidney transplantation.

ESKD is a life-limiting condition.<sup>1</sup> RRT offers a chance for survival, but it isn't a cure and can fail. As technology advances, RRT is increasingly used in children with ESKD. In some cases, however, such as children with multiple health problems or small infants, RRT can be difficult to perform. RRT can also be burdensome for patients and families, with unwanted symptoms and restrictions on daily life. It can also have serious complications.<sup>2</sup> This can lead to difficult treatment decisions for families and clinical teams.<sup>3,4</sup>

In some cases, it is in the best interests of the child not to start RRT and to instead offer conservative care. Conservative care can be described as patient-centred treatment of the child's kidney condition without the use of RRT.<sup>5</sup> It includes managing symptoms or complications of the kidney condition while providing emotional, social and spiritual support to the child and family. As the child's kidney condition progresses, this may also include 'palliative' or end-of-life care.

In the UK, information is collected through the UK Renal Registry (UKRR) on all children with ESKD who receive RRT. Currently, about 1000 children aged 0-18 years use RRT, with 130 new cases each year.<sup>6</sup> We do not know however, how many children reach ESKD who do

not receive RRT. Very little is known about this group of children.

International experts have called for research to identify this group of children, to understand more about their circumstances and how they are cared for.<sup>7-9</sup> As RRT use is increasing in children, understanding what factors play a role in cases where conservative care is chosen will help to understand how to counsel families in the future. It will also help to understand if support provided to these families varies across the country.

<b>Coverage</b>	United Kingdom and Republic of Ireland
<b>Duration</b>	September 2020 to September 2022 (25-months of surveillance) with a 1-year follow-up until September 2023.
<b>Research Questions</b>	<ol style="list-style-type: none"><li>1. To determine the incidence of children with end-stage kidney disease in whom an active decision has been made to manage their kidney disease conservatively without the use of renal replacement therapy.</li><li>2. To descriptively report the patient and disease characteristics of children with ESKD who are managed conservatively.</li><li>3. To describe factors implicated in the decision for conservative management for patients, parents/carers and health professionals.</li><li>4. To describe involvement of the multi-disciplinary team in discussions surrounding conservative care for childhood ESKD and potential variations observed across the country.</li><li>5. To describe the subsequent management and 12-month outcome of children managed conservatively for ESKD.</li></ol>
<b>Case definition</b>	<p>Any incident children aged less than 16 years who develops ESKD during the study period for whom an active decision has been made in the child's best interests not to pursue long-term RRT* and to instead manage the child's kidney disease conservatively (this decision may have been made before or after reaching ESKD).</p> <p><i>*RRT refers to invasive treatments used to substitute the role of the kidneys and includes: Haemodialysis; haemodiafiltration; peritoneal dialysis; renal transplantation; continuous forms of RRT used on Paediatric Intensive Care Units such as continuous venovenous haemodialysis (CVVHD), continuous veno-venous haemodiafiltration (CVVHDF) and slow continuous ultrafiltration (SCUF).</i></p>
<b>Reporting instructions</b>	<p>Please report any cases of children and young people &lt;16 years of age who meets surveillance case definition seen in the last month in the UK or the Republic of Ireland. Please report cases even if you think they may have been reported elsewhere.</p>
<b>Methods</b>	<p>Each paediatrician reporting a child who meets the above case definition of conservative care in paediatric end-stage kidney disease will be sent a clinical questionnaire by the study team.</p> <p>Throughout the study, all patient data will be dealt with in strict confidence, and the families of affected children will not be contacted directly by the study team at any stage.</p>
<b>Ethics approval</b>	South West - Central Bristol Research Ethics Committee (reference: 19/SW/0197); HRA Confidentiality Advisory Group (reference: 19/CAG/0190); and Public Benefit and Privacy Panel for Health and Social Care (reference: 1920-0101).
<b>Support groups</b>	Kidney Research UK ( <a href="https://kidneyresearchuk.org">https://kidneyresearchuk.org</a> ). The Renal Association ( <a href="https://renal.org">https://renal.org</a> )
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