Rare Disease Research UK.

Renal Ciliopathies National Network - CILIAREN

The Renal Ciliopathies National Network – CILIAREN

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Introduction

The renal ciliopathies represent a group of rare inherited kidney diseases affecting around 10% of all patients with kidney failure.

Recently the first drugs have come to the clinic to slow down this disease but treatments that prevent or switch off the disease are still lacking.

AUTOSOMAL DOMINANT POLYCYSTIC KIDNEY DISEASE (ADPKD)
1 : 800 - 2,500 people

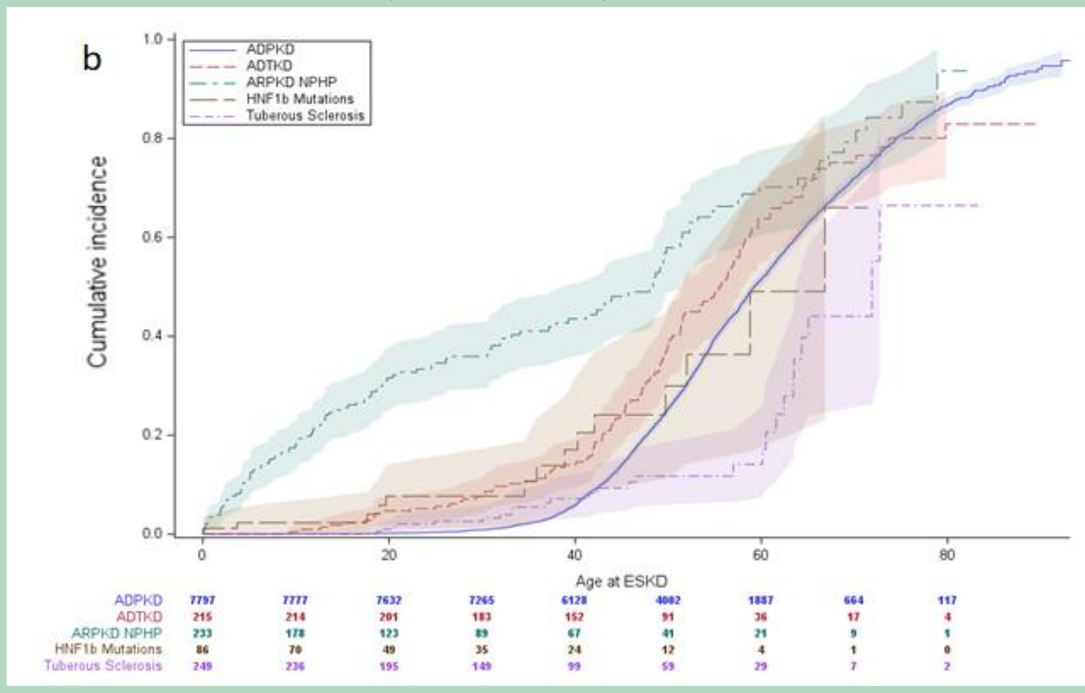
AUTOSOMAL RECESSIVE POLYCYSTIC KIDNEY DISEASE (ARPKD)
1 : 20,000 people

SYNDROMIC CYSTIC KIDNEY DISEASE (i.e. BBS)
1 : 125,000 - 170,000 people

SYNDROMIC CYSTIC KIDNEY DISEASE (i.e. NPHP)
1 : 50,000 - 1,000,000 people

Each a rare disease, collectively represent a significant unmet challenge of our healthcare system

RaDaR Cystic Kidney Disease Data



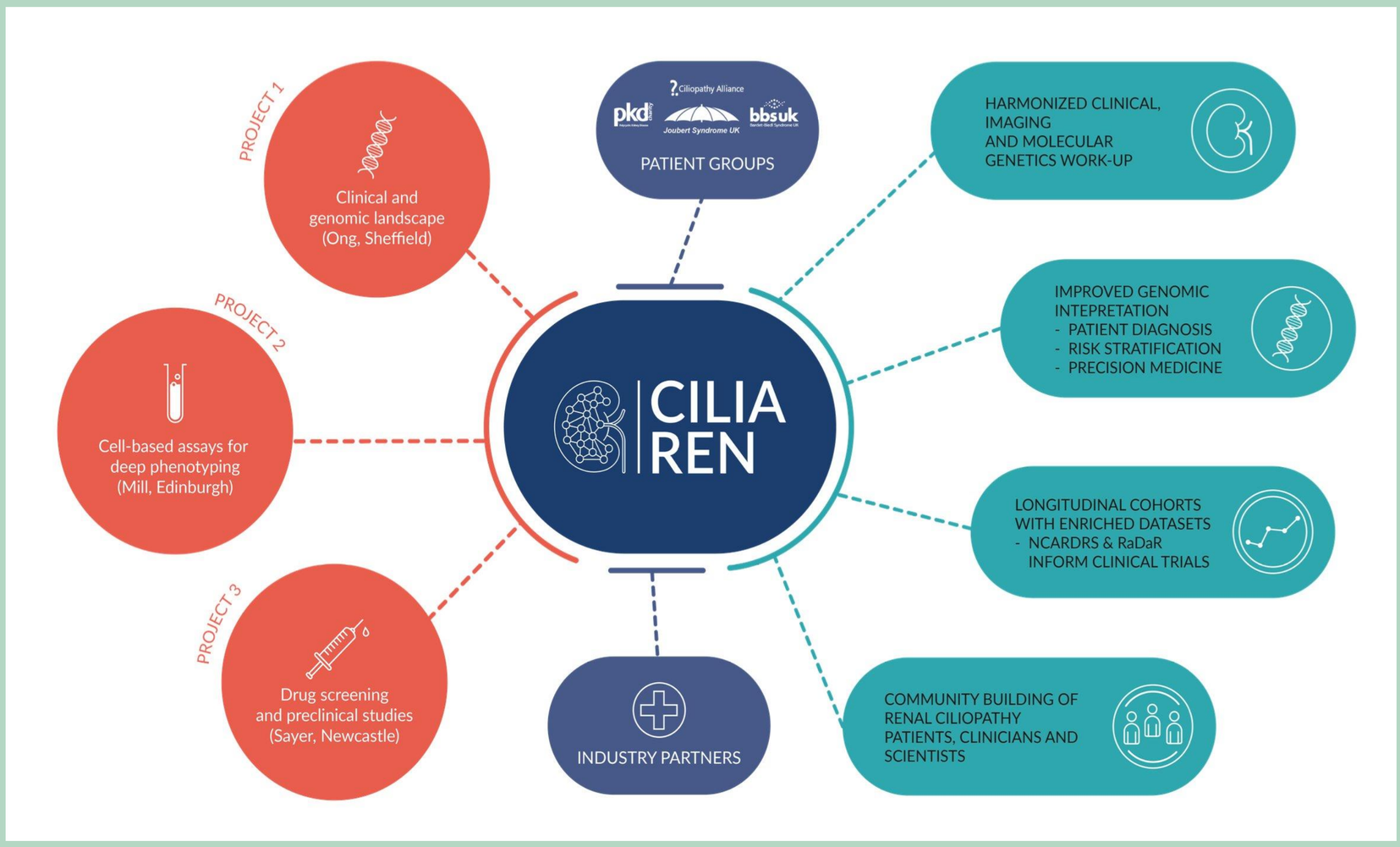
Cumulative incidence of Kidney Failure

RaDaR National Registry of Rare Kidney Diseases

UKKA UK Kidney Association

CILIAREN VISION

- To develop a national network and framework to improve the identification, diagnosis and management of patients with renal ciliopathies
- Educate and train medical practitioners and scientists
- Create a national framework for the identification, investigation and treatment of renal ciliopathies



Patient, Public Involvement, Engagement and Partners

bbs uk Bardet-Biedl Syndrome UK

JOUBERT SYNDROME

pkd charity Polycystic Kidney Disease

AXOVIA THERAPEUTICS

Ciliopathy Alliance

HYBRIDIZE THERAPEUTICS

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UKRI Medical Research Council

NIHR National Institute for Health and Care Research

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