NUTRITIONAL RICKETS PRESENTING TO SECONDARY CARE <16 YEARS OF AGE
(Short study name: Nutritional rickets presenting to secondary care)

Abstract
Rickets is unique to growing children and adolescents and occurs when growing bones do not develop adequately. As a result the child’s bones soften which can lead to distressing short-term (e.g. pain, delayed walking) and sometimes long-term consequences (e.g. deformed limbs needing surgical correction, difficulty with childbearing). Rickets is the commonest childhood complication of vitamin D deficiency (VDD) and is caused by a lack of dietary calcium or problems with the supply, metabolism or utilisation of vitamin D. The disease can be recognised in children and adolescents by specific clinical signs and/or bone x-rays. There is little data on the number of rickets cases in the UK with the last national UK survey of rickets conducted in 1945. The limited data available to date shows that VDD in the UK is steadily increasing. This study will investigate the incidence of nutritional rickets in children under the age of 16 presenting to secondary care in the UK and Republic of Ireland. The study will also identify and describe the characteristics and clinical management of these affected children.

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Background
Rickets was a common Victorian disease and eradicated in the UK by the 1950’s by food fortification, cod-liver oil supplementation and other environmental changes. In recent years it has re-emerged as a major public health concern world-wide, particularly in immigrant, non-Caucasian children. Risk factors for the disease include pigmented skin, lack of sun exposure in high latitude areas, pollution, cultural and religious practices preventing sun exposure, exclusive prolonged breastfeeding, and vitamin D deficient mothers. A Canadian Paediatric Surveillance Unit Study (2002-2004) identified 104 new cases of VDD presenting with significant morbidity including limb deformities (42%) and fractures (11%). The annual incidence was estimated at 2.9/100 000 children. An Australian Surveillance Paediatric Unit Study (January 2006 to July 2007) identified 398 children under 15 years, with VDD. The annual incidence was 4.9/100 000. A Glasgow Hospital retrospective cohort (2002 to 2006) identified
160 cases of symptomatic VDD, 40% with evidence of rickets. All 3 countries have active health campaigns addressing VDD, showing variable success in decreasing the incidence. Nutritional rickets does however remain a preventable disease by sensible sun exposure or vitamin D supplements.

**Coverage**
United Kingdom and the Republic of Ireland (ROI)

**Duration**
March 2015 – March 2017 (25 months surveillance)

**Research Questions**
- To determine the incidence of nutritional rickets resulting from VDD in children up to 16 years in the UK and ROI
- To describe the prevalence of various factors known to influence the development of nutritional rickets (including feeding, vitamin D supplementation, latitude/region) in affected children
- To describe the presentation of nutritional rickets including the symptoms, clinical and radiological signs of affected children
- To describe the clinical management and referral patterns of affected children

**Case definition**

**Clinical Rickets** with any of the following:
Leg deformity (bowing or knock-knees)/Swollen wrists or knees or ankles or ribs (Rachitic Rosary) **AND** 25OHVitamin D <25nmol/L with one or more abnormalities of serum calcium, alkaline phosphatase, phosphate, parathyroid hormone.

**OR**

**Radiological Rickets** with widening, cupping, splaying of metaphysis (of any long bone) **AND** 25OHVitamin D <25nmol/L

**Exclusion Criteria:**
- Vitamin D dependent rickets e.g. 1α-hydroxylase deficiency - vitamin D resistant rickets e.g. familial or X-linked hypophosphatemic rickets.
- Rickets associated with other chronic diseases e.g. malabsorption, liver disease, chronic renal disease
- Metabolic bone disease of prematurity (infants whose corrected age is < 3 months at presentation, who were born < 36 weeks gestation and weighing <1.5kg).

**Reporting instructions**
Please report any cases of children 0-16 years in the past month presenting with either clinical or radiological rickets as defined by the case definition.

**Methods**
Paediatricians reporting a case through the BPSU orange card system will be emailed a clinical questionnaire. Clinical questionnaires are to be completed and submitted online.

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**Support Group**
Contact a Family, 209-211 City Road, London, EC1V 1JN. Details available at www.cafamily.org.uk.

**Ethics approval**
This study has been approved by NRES Committee London - West London & GTAC (REC reference: 14/LO/2221; IRAS ID: 144785) and has been granted Section 251 HRA-CAG permission (CAG reference: 14/CAG/1042).

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