

# Australian Paediatric Surveillance Unit STUDY PROTOCOL

COMMENCING APRIL 2015

**Chronic Fatigue Syndrome (CFS) Study** 

### **BACKGROUND**

Chronic fatigue syndrome (CFS) is characterised by significant fatigue accompanied by a range of symptoms including; pain, cognitive, sleep, and immune symptoms. Epidemiological studies suggest CFS is far less common in children and adolescents compared with adults. There is wide variation in the few available estimates of incidence and prevalence of CFS in children and adolescents less than 18 years of age. The Centers for Disease Control and Prevention (CDC) criteria for CFS are the most widely used criteria internationally and were also used by the Dutch Paediatric Surveillance Unit (DPSU) in a relatively recent study to estimate incidence rates of paediatric CFS in The Netherlands<sup>1</sup>. This study reported the incidence of paediatric CFS in The Netherlands to be 12 per 100 000 (10 - 18 years). Population-based studies using the CDC criteria estimate the prevalence of CFS in children and adolescents in the range of 60 per 100 000 to 190 per 100 0000<sup>1-3</sup>. Prevalence rates are estimated to be much higher when strict criteria are not adhered to, with reported estimates of 338 per 100 000<sup>4</sup> and 2070 per 100 000<sup>5</sup>. There are no incidence or prevalence estimates for Australian children or adolescents. Our study aims to investigate the incidence of CFS in children and adolescents using the Australian Modification of the CDC criteria as developed by the working group under the auspices of the Royal Australasian College of Physicians<sup>6</sup>. There are other more recently proposed criteria for CFS<sup>7,8</sup>; however to date these criteria have not been applied in epidemiological studies in children and adolescents. A number of questions in the study questionnaire will allow us to determine whether the reported cases also meet the more recently proposed diagnostic criteria<sup>7,8</sup>.

This surveillance will contribute to knowledge about CFS in children by providing the first ever estimate of the incidence of CFS in Australian children aged < 18 years presenting to paediatricians and other child health professionals. It will also help to describe clinical and demographic features and treatments/interventions for CFS, currently used in Australia. A better understanding of current approaches at a national level is important to inform guidelines and policies for the diagnosis and management of CFS and to identify priority areas for improved education and research to support improved diagnosis and management of paediatric CFS across Australia.

# **STUDY OBJECTIVES**

- 1. To estimate the incidence of CFS in Australian children and adolescents.
- 2. To describe the demographic features of CFS in Australian children and adolescents.
- 3. To describe the clinical features of CFS and associated features such as comorbid psychiatric or medical conditions at presentation.
- 4. To describe the current management practices for children and adolescents with CFS including investigations and interventions.
- 5. To evaluate whether the clinical features of CFS in identified children are consistent with other proposed CFS diagnosis criteria.

Please see over for case definition

### **CASE DEFINITION**

Any child or young person <18 years seen during the previous month newly diagnosed with CFS as defined by the Australian Modification of the Centres for Disease Control and Prevention Case definition<sup>6</sup>

# CFS is defined by:

- 1. Severe chronic fatigue for 3 or more consecutive months.
- 2. The fatigue significantly interferes with daily activities.
- 3. The individual concurrently has 4 or more of the following 8 symptoms:
  - post-exertion malaise lasting more than 24 hours
  - unrefreshing sleep
  - significant impairment of short-term memory or concentration
  - muscle pain
  - pain in the joints without swelling or redness
  - headaches of a new type, pattern or severity
  - tender lymph nodes in the neck or armpit
  - a sore throat that is frequent or recurring

### **Exclusions:**

A diagnosis of CFS cannot be made in children or adolescents where the fatigue is due to ongoing exertion or other <u>diagnosed chronic medical conditions</u> associated with prolonged fatigue e.g. malignancy

## **INVESTIGATOR DETAILS (\*Principal Investigator and contact person)**

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