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Disclosure of Interests:
H. Dagfinrud1, R. H. Moe1.


BESIDE THE IMPACT OF ACCURATE INCIDENCE AND PREVALENCE ESTIMATES FOR FAMILIES OF CHILDREN WITH JUVENILE IDIOPATHIC ARTHRITIS

R. Beesley,1 1Juvenile Arthritis Research, JAR Project, Tonbridge, United Kingdom

Background: Juvenile Idiopathic Arthritis (JIA) is a heterogeneous group of autoimmune disorders characterised by chronic joint inflammation, affecting children and young people (CYP) under the age of 16. Recent analysis in the UK [1] has provided an update to the estimated incidence and prevalence of JIA.

Objectives: Whilst the policy and healthcare benefits of accurate incidence and prevalence rates are understood, this patient- and parent-led qualitative project sought views from parents of CYP with JIA to understand whether knowing accurate estimates of incidence and prevalence are important to them.

Methods: Parents of CYP with JIA, all members of a small online group on social media, were asked whether knowing accurate rates of JIA were important to them, and why. Responses were collated and summarized.

Results: Whilst a few respondents felt it did not matter to them what the overall rates of JIA were, focusing instead on their own personal experience with the condition, the majority did want to know and gave consistent reasoning. They advised that, when your child is diagnosed with JIA, it is a very isolating experience. Most parents have never heard of the condition before, and being told your child has arthritis is a frightening time (especially if you then become aware of some of the significant long-term effects, such as potential continuation of disease into adulthood and possible joint damage, and the side effects of treatment, and social impacts of the disease [2, 3]). Whilst direct support is available to families affected by JIA (www.jarproject.org/hope), understanding prevalence rates can help reduce mental health burdens on patients and parents and reduce feelings of isolation. Families also advised that they want to know numbers of children with JIA so we collectively can get a better understanding of the cause, the trends, and the possible reasons behind changes. Knowing accurately the numbers of children with JIA can help to raise awareness; current lack of awareness in society and primary care contributes to delays in diagnosis and potentially worse clinical outcomes [4]. In addition they reported the need for appropriate resourcing of paediatric rheumatology and support services, and the political and financial discussions that must take place to enable that to happen need to be supported by evidence.

Conclusion: Overall, parents do want to know how many other children have JIA. It takes some of the isolation and anxiety away to know you are not alone. It matters because knowing there are other parents in the same situation as you can help reduce anxiety and loneliness. It matters, because knowing there are researchers focussing on JIA helps remind you that work is underway to better understand JIA, its causes, and improved treatments which will eventually lead to improved care for children with the condition. It matters, because it can help target resources appropriately. It matters, because raising awareness is more effective if we know how many people are affected by a chronic condition. And it matters, because as improved treatments are developed we want to be able to see the number of children categorised as having active JIA to reduce and health outcomes for each child to improve.

REFERENCES:

Disclosure of Interests: None declared


POS0089-PARE ORGANIZATION, INFLUENCE, AND IMPACT OF PATIENT ADVISORY BOARD REPRESENTATION IN PRIVATE REHABILITATION INSTITUTIONS – AN EXPLORATORY CROSS-SECTIONAL STUDY

J. Sagen1, E. Børsund2, A. E. Simonsen3, A. Harberstad4, I. Kjeken1, H. Dagfinrud1, R. H. Moë5. 1The Deacon's Home Hospital, Norwegian National Advisory Unit on Rehabilitation in Rheumatism, Oslo, Norway; 2Oslo University Hospital, Oslo, Norway, Department of Digital Health Research, Division of Medicine, Oslo, Norway; 3Rasmunnet Rehabilitation Center, Patient Advisory Board, Jarem, Norway; 4The Norwegian Federation of Organisations of Disabled People, Research and Patient Participation, Oslo, Norway

Background: Patient participation (PP) organised as patient advisory boards (PABs) is a statutory part of health care institutions in Norway (1). There is limited agreement on how to engage PABs in a meaningful manner (2). More knowledge on how PAB representatives experience patient engagement (PE) is needed.

Objectives: To explore how PAB representatives engage in PABs with regard to organisation, influence, and impact on decision-making processes and service delivery.

Methods: PAB representatives recruited from rehabilitation institutions, representing all four health regions in Norway completed a PE evaluation tool. The tool is tested for reliability and content validity with good results and comprises 35 items including four main domains: policies and practices, participatory culture, collaboration, and influence and impact that provided responses about PE-levels (3). Categorical data were summarized to modal scores using frequencies and percentages, and response categories were collapsed from five to three. The collapsed categories were divided into PE-levels: barrier, intermediate, and facilitator (Table 1). Free-text responses were analysed according to principles of manifest content analysis, summed up, and used to complete the results of the scores. Free text responses were analysed using Quirkos version 2.4.7.

Results: Of the 150 contacted PAB representatives, 47 (32%) responded. PAB representatives’ mean age was 60.5 (min-max 30 - 80), 62% were female and a majority (81%) had prior experience with PP. The results showed that 75% of the participants agreed that patient-centered care was strengthened as a result of PE. Three out of four main domains scored indicating a facilitating PE-level (Table 1). The domain, influence and impact scored with an intermediate PE-level. Regarding influence and impact, half of the participants did not know PE input had influenced management decisions, and 60% had rarely identified any PE contributions. The results from free text analyses showed that PE was coded as a facilitator seven times, and as a barrier to PE 26 times. The most frequent barrier was exclusion of PAB (13 codes), and the most coded facilitator was inclusion of PAB (3 codes).

Conclusion: Findings indicate that PAB representatives are satisfied with how rehabilitation institutions organise PABs. Unclear adherence to the values and principles of PP may hinder influence and visibility from PE contributions.

REFERENCES:

Table 1

<table>
<thead>
<tr>
<th>Items</th>
<th>Domain</th>
<th>Modal PE-level</th>
<th>Mode</th>
</tr>
</thead>
<tbody>
<tr>
<td>n (%)</td>
<td>(min-max)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
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<td>---</td>
</tr>
<tr>
<td>5</td>
<td>Policies and practices</td>
<td>Facilitating</td>
<td>125 (53.2)</td>
</tr>
<tr>
<td>8</td>
<td>Participatory culture</td>
<td>Facilitating</td>
<td>199 (53)</td>
</tr>
<tr>
<td>2</td>
<td>Collaboration</td>
<td>Facilitating</td>
<td>35 (36.5)</td>
</tr>
<tr>
<td>6</td>
<td>Influence and impact</td>
<td>Intermediate</td>
<td>125 (44.4)</td>
</tr>
</tbody>
</table>

Questions not presented in the table consist of background items, items related to final thoughts, and five questions with free text fields. A yes or no question related to the domain policies and practices is not included in the table.

Before collapsed, 15 items were valued: Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree, don’t know. Seven items valued 1-5: never, seldom, some of the time, all of the time, don’t know.

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