NSW Paediatric Rheumatology Network
Implementation of the Model of Care

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Background
NSW Paediatric Rheumatology Model of Care, developed by the Agency for Clinical Innovation (ACI) was launched in 2013.

In July of 2015, Sydney Children Hospitals Network (SCHN) and ACI jointly funded a project officer to implement the Model of Care.

Aims
- To improve physical health & well-being of children & young people.
- To improve health education & support services for children & young people and their families.
- To establish a culture of quality improvement.
- To improve education for health professionals in the recognition and management JIA.
- To develop & maintain a sustainable service.

Phase 1 NSW PRN project was guided by a Steering Committee with representation from patients and nongovernmental agencies. The focus of Phase 1 is patients with juvenile idiopathic arthritis (JIA).

The patient with JIA’s journey was mapped and compared to best practice.

Methodology
Phase 1 of the project used the clinical redesign methodology. This poster will discuss:
- Diagnostic Phase
- Solution Design
- Implementation Planning and
- Implementation

Diagnostics
Jack’s Story
An 11 yr. old boy presents from a regional area of NSW with an 18 month history of pain and a limp. His Mum repeatedly presented to local GPs. Switched GP twice before final referral to SCHN.

Prior to this, he was an active boy, played sports all year round. 12 months prior to referral, he stopped playing all sports due to pain. He began missing one to two days of school a week in Year 6.

On presentation, he has evidence of arthritis in one ankle, both knees, a wrist and cervical spine.

Optimal management includes intra-articular steroids however next available joint injection list appointment slot is in eight weeks.

Patient Journey

Patient Journey Timeline

Journey Timeline

<table>
<thead>
<tr>
<th>Journey</th>
<th>Time to Referral</th>
<th>Time to See Rheumatology Team</th>
<th>Time to Joint Injections</th>
<th>Time to Uveitis Surveillance</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHW</td>
<td>3-12 months</td>
<td>2 weeks</td>
<td>2 mos. - no list</td>
<td>&lt; 4 weeks*</td>
</tr>
<tr>
<td>SCK, R</td>
<td>3 - 12 months</td>
<td>2 weeks</td>
<td>2 mos. – 1 list mo.</td>
<td>10 mos. waiting list*</td>
</tr>
<tr>
<td>BSPAR</td>
<td>&lt; 10 weeks</td>
<td>&lt; 4 weeks</td>
<td></td>
<td></td>
</tr>
</tbody>
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Identified Strengths
- SCHN – once referred, timely appointment to Rheumatology service
- At CHW – timely uveitis surveillance

Identified for Improvements
- Early recognition of illness & referral to rheumatology
- Care coordination/education
- Access to rheumatologist & interdisciplinary care

Diagnostics

Solution Design / Implementation

Next Steps - Phase 2

Acknowledgments to the NSW Paediatric Rheumatology Project Steering Committee:
Sydney Children’s Hospital Network, 1 John Hunter Children’s Hospital, 2 Agency for Clinical Innovation, 3 John Hunter Children’s Hospital, Arthritis NSW 4

ACI NSW Agency for Clinical Innovation

Diagnostic Phase
- BSPAR Standards of Care for children and young people with juvenile idiopathic arthritis
- BSPAR 1,2

Diagnostic
- Diagnosis of uveitis – patients seen within 2 weeks

Joint Injections
- Joint Injections
- Optimal management includes intra-articular steroids however next available joint injection list appointment slot is in eight weeks.

Uveitis Surveillance
- CHW – timely uveitis surveillance
- SCHN – once referred, timely appointment to Rheumatology service
- At CHW – timely uveitis surveillance

Care Coordination
- SCHN – once referred, timely appointment to Rheumatology service
- At CHW – timely uveitis surveillance

Solution Design / Implementation

Next Steps - Phase 2

Additional Rheumatologist FTE #

Systematic review of the literature
- Search strategy:
  - MEDLINE
  - Scopus
  - CINAHL
  - Embase
  - Cochrane Library
  - Other databases as appropriate

Health Pathways
- HealthPathways created and in the process of being rolled out across NSW

Early Recognition of Illness
- Health Pathways created and in the process of being rolled out across NSW

Service Enhancement
- Addition of a CNC to the Paediatric Rheumatology Team

Educational resources developed
- SCHN Intranet – Patient and Family Resources section developed
- “What is JDM: a resource for patients and families about Juvenile Dermatomyositis”
- Paediatric Rheumatology NSW Website – under development

Next Steps - Phase 2

Evaluate Impact of HealthPathway
- Evaluate & implement the impact of the CNC Role –
- Health priorities
- Uveitis surveillance
- Greater access to joint injections with nitrous oxide & general anaesthetic
- Development of data collection system to support the development of a QI & research