

## 1. Overview

This purpose of this workshop was to create a plan for a national interactive workshop to discuss topics related to patients and families with JIA. This workshop included young people and adults who had various experiences in transitioning of care from young person's rheumatology services to adult rheumatology services.

Date:	26/11/2016, Saturday
Time:	11am – 2.30pm
Location:	Maldron Hotel, Galway
Facilitated by:	Ms Olive O'Connor
Appointed by:	ICAN; Ms Wendy Costello
Note keeper:	Ms Bernie Ffrench
Attendees:	8 Participants in Total

## 2. Introduction

### 1.1. Group Guidelines

- Guidelines for the group were set by participants at the beginning of the session:
  - Everyone could feel safe and not feel they should discuss anything they're not comfortable with
  - Everyone would accept that they may feel emotional and that this was okay
  - That personal information would not be shared with anyone outside of the group
  - That everyone would remain confidential
  - No judgement on anyone's opinions or viewpoints
  - Everyone could feel free to move about at any time
  - That a note keeper would be assigned
  - That people could answer their phones outside of the room
  - Everyone would get the chance to talk
  - Everyone would be kind to one another
- A note keeper was agreed and assigned by the group.

### 1.2. Aims of this Workshop

- An outline of the subjects to be discussed was shared:
  - What can we (as patients and carers) do to help our teams?
  - What is transition, and what should it be?
  - What would have helped (looking back in time)?
  - What would we like to achieve at our national workshop?

## 3. Opening Session

### 1.3. Experiences & Issues

- Participants were given the opportunity to discuss current issues related to JIA. Several topics emerged:
  - **Medications** (Prescribing and Information)
  - **Symptoms** (Managing and discussion)
  - **Transition of Care** (Juvenile to Adult)
  - **Empowerment** (Patients and carers)
  - **Communication** between patients and HCPs<sup>1</sup>; and with family and friends; terminology used
  - **Stigma** (Feeling different to peers)
  - **Perceptions** (Family and HCP's perceptions of symptoms and diagnosis)
  - **Causation** (Information about the causes)
  - **Education** (Difficulty in informing schools – college have excellent system)
  - **Employment** (Fears related to being able to work / get / retain a job)
  - **Social Life** (Not being able to participate in social activities)
  - **Self-Management** (Medications, Symptoms and Treatments - Practicalities)
  - **Self-Care** (Looking after emotional, physical needs)
  - **Co-Morbidity** (Managing Arthritis with other conditions)
  - **Stereotyping** (Presumptions that symptoms caused by Arthritis only)
  - **Paternalistic Care** and Shared decision making
  - **Human Centred Care** (Non-holistic approaches not considered – family centred care not applied)
  - **Research** (Genetics, symptoms and family history)

### 1.4. Personal Emotional Impact

- Participants were given the opportunity to share their stories. A discussion related to how people *felt emotionally* as patients or carers arose:
  - **Guilt:** Both patients and carers felt certain elements of guilt. This was related to the guilt of being sick and how it affected parents, care givers and siblings. It also related to parents and caregivers as they felt they couldn't help their child.
  - **Fear:** All participants had experienced fear with relation to the diagnosis of JIA. This fear was related to the taking and impact of medications; the fear of injections; the fear of long term side effects and the fear of their future. Fear also arose about the future of patients becoming "infertile" because of medications.
  - **Shame and Resentment:** Many of the young people felt ashamed with having a condition. This was often related to stigma and "not fitting in" with everyone else. Many resonated with "feeling different" to other people and resented having a condition.
  - **Lonely:** All participants at various stages felt lonely. Parents felt isolated when compared to other parents who had "healthy children" and young people felt lonely because they could not share their experiences with friends and/or had to give up social activities because of their illness.
  - **Overwhelmed:** Nearly all participants had felt overwhelmed at various stages prior to, during and post diagnosis. Many of this was related to the self-management of the conditions (medications, appointments, symptoms) and the worry of their future. Many adults struggled with trying to juggle between work, family, relationships and caring for a sick child.
  - **Unassured:** Many participants felt unassured with relation to their diagnosis, communications and/or treatments. This often left a feeling of mistrust between patients and their HCP's.
  - **Confidence:** Many felt their confidence was affected since diagnosis.

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<sup>1</sup> HCPs = Health Care Professionals

# ICAN WORKSHOP – SESSION 1

## Some of the statements made on the day by participants:

"It is hard to stand up for yourself and when you do it can often have a negative impact."

"Initially learning of having a long-term condition scared me. I worried about my future."

"I worried if I would be able to have children after taking the medications."

"I stopped taking my medications because I was so afraid of the injections"

"Sometimes doctors mistook my symptoms as being arthritis but I found I had another condition"

"Colleges give fantastic support for disabilities, why do schools not have the same approach?"

"I resented having arthritis, it took me a long time to accept it and to realise I would have to live with it".

"Barriers are often put in place by others, not by ourselves (e.g. schools)"

## 1.5. Discussions re: Transition of Care

- **Age for transition of care:** The group was asked what age transition should start at:
  - A proposal that the first-time transition is discussed with a young person should ideally be between 6th class and first year as this is a time when a lot of new change happens for young people and they should consider how secondary school may impact on them. The age itself was not that important, more starting transition as the young person in transitioning in life.
- **Who should be involved** in transition of care programme?
  - The whole group agreed that schools need to be involved in this process so that they can better understand the needs of the young person and help identify opportunities for them to transition to secondary school easier.
  - A multidisciplinary approach between juvenile rheumatology specialist and adult specialists would be considered best practice.
  - Full involvement of care givers and families would be considered a necessity.
  - Working with specialist charities would also be considered important as they would have insights and domain knowledge.
- **What is required** for transition of care?
  - It was agreed by the group that there should be a national database of all rheumatology teams in Ireland showing the services they have available to them, so that patients and caregivers could make choices based on the needs of their child.
  - It was also discussed that a national transition care coordinator would be essential to deliver this output.
  - Information toolkits was mentioned numerous times.
  - Using the YARD model could be appropriate: Paediatric Clinic – Teen Clinic – Adult Clinic

## 4. Solutions to Challenges

### 1.6. Information (Collaborative Approach)

- Information leaflet for patients and families (x 2)
- Toolkit for Specialists
- Toolkit for Schools

### 1.7. Pathways – Health Care Professionals

- Develop a national transition care pathway toolkit for JIA, building upon the frameworks that are proven i.e. Belgium and Germany.
- Self-Management resources promoted at the point of care by HCPs

### 1.8. ICAN Solutions

- ICAN could consider a sibling support group – e.g. Facebook or other platforms
- ICAN could consider appointing a National Transition Coordinator who could overview services at a national level and share this information with rheumatology teams which they can then pass on to parents.

## 5. Agreed Outputs

### 1.9. Timelines

- Date for workshop February 2017
- Date for completion of Information Toolkits May 2017
- Date for completion of Pathway Toolkit August 2017
- Launch all outputs 12<sup>th</sup> September 2017 – National Awareness Day

## 6. Proposals

### 4.1. Format of Workshop

- “Transitions Through Life, Not Just Through Arthritis” – this was agreed by the group.
- Date: February 2017
- Two-day event – this was agreed by the group. An evening and a morning.
- Story telling by a young patient followed by analysis by a facilitator.
- Various talks and workshops related to Transition of Care – Visions, Challenges and Solutions
  - Self-Management and Self-Care
  - Shared Decision Making
  - Medication Management
  - Family Centred Care
  - Personal Impact
  - Information and Communication

## 7. Attendees

### 4.2. End-users

- Parents, families and patients who need supports for JIA

### 4.3. Facilitators

- Facilitators are ICAN Committee members
- Workshop facilitator – Olive O'Connor

### 4.4. Speakers

- TBC

### 4.5. Health Professional Stakeholders

- St Vincent's, Tallaght, Crumlin & Temple Street are the acute hospitals which specialise in JIA
- Persons who should be involved and attend are – GPs, Pharmacists, Psychologists; Dentists / Orthodontists; Clinical Nurse Specialists; JIA teams; Rheumatologists (adult and juvenile); Physiotherapists; Occupational Therapists; Public Health Nurses; Ophthalmologists; Triage teams; Emergency doctors.