

## 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 living with JIA. This workshop included multi-disciplinary health professionals; adults with lived experiences as patients or carers; and advocates who work (paid/voluntarily) in rheumatology services (adult and juvenile). All participants had a keen interest and passion in the transitioning of care from young person's rheumatology services to adult services.

Date:	25/03/2017, Saturday	Time:	11.00am – 3.00pm
Location:	Aisling Hotel, Dublin	Facilitated by:	Ms Olive O'Connor
Appointed by:	ICAN; Ms Wendy Costello	Note keeper:	Ms Bernie Ffrench

## 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
  - Everyone could feel free to move about at any time
  - That people could answer their phones outside of the room

### 1.2. Aims of this Workshop

- An outline of the subjects to be discussed was shared:
  - Transition Models currently in use and how are they being done?
  - What age is Transition beginning and ending?
  - What Multi-disciplinary teams are involved at each Adult Transitioning Hospital?
  - What are the differences between Public and Private Rheumatology?
  - What Barriers are seen by the Professionals to care?
  - What would the Professionals like to see in our National Workshop?

### 1.3. Participants Present (14 in Total)

- Consultant Rheumatologist - Paediatric Service
- Rheumatologist Nurse Specialist – Adult Service
- Advanced Rheumatologist Nurse Specialist - Paediatric Service
- Chairperson of JIA Advocacy Group - Parent of Child with JIA
- Post-Doctoral Researcher: Pain/Sexual Health Promotor
- Nurse Lecturer: Mum to child with JIA
- Doctoral Researcher in Child and Family Health: Patient: Crones disease and Fibromyalgia
- Special Needs Assistant, Primary School: Parent to JIA child
- Dental Hygienist in Specialist Practice/ Acupuncturist: Patient and family member with JIA
- Mum of Adult Child with JIA (UK): Diagnosed since childhood
- CCA Representative (UK): Patient of JIA since childhood
- IT Manager (Private Acute Hospital): Patient of JIA since childhood
- Young Adult (Occupation: Hairdresser): Patient of JIA since childhood
- Parent and Adult: Child with JIA and a mum of child with JIA

## 3. Opening Session

### 1.4. Recurring Themes through Story Telling

- Participants were given the opportunity to share their story and discuss their experiences related to JIA. Several topics emerged:
  - **Advocacy** (Parent having to speak for children – “neurotic mum/dad”)
  - **Empowerment** (Patients and carers)
  - **Employment** (living with JIA and working/getting employment)
  - **Attitudes** (Towards JIA as opposed to other conditions)
  - **Network** (Crucial aspect for parents and children)
  - **Family Impact** (Siblings, marriages, relationships)
  - **National Services** (Different services across Ireland)
  - **Communication** between patients and HCPs<sup>1</sup>; and with family and friends; terminology used
  - **Multiple Conditions and JIA** (Multiple medications, HCP’s, symptoms)
  - **Listening** (Feeling Heard and not just listened to)
  - **Medications** (Administration, self-management, prescribing)
  - **Transition** (Varies across services – mainly works in Dublin hospitals)
  - **Adult Services** (Putting children into an adult service/unit/outpatient department)
  - **Age of Transition** (Varies internationally; also changes throughout lifespan)
  - **Physical Perceptions** (Visually “people” cannot see the disease – HCP’s said they have the “best looking” waiting room – all patients look well)
  - **Emotional Impact** (Fear of change re: transition, control issues, phobias)
  - **Dental** (Impact JIA has on dental presentation)
  - **Misdiagnosis** (Waiting to get diagnosis has long lasting impact – feeling believed)
  - **Fighting for Services** (Access to paediatric rheumatology/treatments/medications)
  - **Private vs Public Services** (Inequality for those with income)
  - **International Representation** (Groups globally sharing information/models of care)
  - **Resources** (lack of standardised resources [staff/units/finances/policy])
  - **Impact on child** (Trauma not being able to be “normal child”)
  - **Individualised Care** (Treating the person, not the patient)
  - **Waiting Lists** (Access to teams/treatments and outpatient departments)
  - **Collaboration** (Between health professionals, charities and policy)
  - **Self-Management and Self-Care** (Promoted at the point of care)
  - **Psychology Support:** (Available immediately from onset of conditions)
  - **Health Records:** (All families should have access and they need to be integrated)

---

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

## 1.5. Experiences of Parents and Adult Patients/Carers

- Participants were given the opportunity to share their stories. A discussion related to how people *felt emotionally* as patients, professionals or carers arose:
  - **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.
  - **Phobias:** Children can develop “Needle Phobia “ from bad experience
  - **Neurotic Parents:** parent described herself as “pushy” – feeling listened is key
  - **Negative Perceptions:** Parents feeling like they are neurotic or overreacting to child’s symptoms
  - **Long lasting Impact:** Parent/ patient feeling angry/upset/frustrated/worried because of how they may have been perceived as neurotic parents.
  - **IT administrator in hospital and patient with JIA/RA:** Involved in this focus group because suffered “Emotionally “never had psychology and wants to change that for others
  - **Advocacy:** Navigating the system of managing own child through favours, by being assertive and sometimes aggressive. Wants the Professionals to “Listen”.
  - **Living outside of Dublin:** Transition is not so easy outside of catchment area, limited knowledge on what services available nationwide
  - **Family Journey:** It is not just the child that is impacted by JIA; it affects parents and siblings too
  - **Need for Empathy:** Need for understanding the fears from leaving a children’s hospital to an adult service
  - **Overwhelming:** Living with a Chronic illness is “enormous”
  - **Late or Misdiagnosis:** Poor experience of getting a diagnosis: late diagnosis causing people to suffer mentally, physically and emotionally – one patient was left 5 years undiagnosed.
  - **Guilt:** Parents can suffer watching children suffer, and having to administer Methotrexate “Tricking in Food” and having to cajole them into accepting treatments
  - **Pride:** Parents very proud of children for what they have achieved given challenges
  - **Willingness to help others:** Involved in this focus group because of suffering “Emotionally” never had psychology and wants to change that for others
  - **Relationships:** Many emotionally struggle if they have a poor relationship with their health professionals
  - **Acceptance:** Big emphasis- once child accepts it gets easier getting support to get there is important
  - **Information Sharing:** “Why is there a lack of information across the services? “

## 1.6. Experience from Professionals View Point

- Current service is under resourced adding pressure to all HCP's and services has long lasting impact
- Under pressure – “heart sink” moments
- Feeling “Demoralised”
- A lot of administration work takes time away from patients: D.A.R.E (Disability Access Route to Education) forms.
- System failures has negative impact on professionals - Nice Guidelines are important in helping the system failure.
- Finances to fund is necessary to system running properly
- Communication breakdown huge issue – connected IT needed
- Professionals themselves have been on the receiving end of the inadequate service. Their own children with injuries and JIA referred too young to Adult Services.
- No full MDT and some only have 1- 2 Consultant Rheumatologist and others on 20% Rheumatology appointment.
- No up to date database of Named Rheumatology Nurse Specialists whom they themselves or we as a charity could contact.
- SNA not given training on JIA or other chronic childhood illnesses
- “Sick-Child” reference is a term that shouldn't be used
- Services completely different in other countries such as UK or America (NY)

## 1.7. Learnings for JIA care in general

- Other specialist services such as: Endocrinology, Cardiology and Oncology have years on Rheumatology
- Believes that use of Private Health Insurance has benefits
- Radiology is one area where quicker access occurs and because of the Central System x-rays and scans can be reviewed
- Slotting into public system can occur after using private insurance
- Adult rheumatology nurse coordinates care with the Rheumatologist, Patients and Parents and various other multi-disciplinary team members.
- Important to help the patient understand and manage their condition through support, advice and education.
- A HCP's "Business Card "can offer a personal point of contact..." We endeavour to respond etc....."
- "Continuity of Care" much needed across Ireland
- Patients should be referred to Advanced Nurse Practitioner by rheumatologist to solely manage children's care – this is done in adult services.
- Education for professionals in pain management essential
- HCP's who may have experience in living with/caring for children may show more empathy
- Important to know the person, not just the patient
- Since 2000 there is a positive reassurance in how far treatment of various rheumatological conditions has improved: better drugs and more use of a multi-disciplinary approach has reduced the numbers of UK referrals in 10+11yr olds for protracted surgeries etc. Currently her role involves education of adolescents on better self-management of their condition and lifestyle choices such as smoking, drinking, sexual health etc. Her approach centres on a gentle chat around these topics and she has found that they will open up using this approach.
- Support needed by Parents by charities and advocacy groups - e.g. iCAN support up to 600 families daily. A network helps others connect to share and get help on their journey through JIA: Charities can help shape a child's journey through JIA, along with the Paediatric team. Parent Network helps inspire other parents and provide tools to help manage. ENCA-( European Network Children's Arthritis- values the shared knowledge like in Slovenia some adolescents are kept in Paediatric care as biological drugs are unavailable in Adult Services. JIA Children need other JIA children, but can only access them in a positive way and iCAN can facilitate this through "Laugh and Learn "days out and get together.
- There is a belief that there is an excellent service available – needs to be widespread
- Psychological support is invaluable to help with all aspects of the disease, builds empowerment, communication and confidence
- Highlighting JIA to media and Politian's is important
- Psychology is important in management of the disease and helped her son with " Needle Phobia " and " Emotional Trauma " of restricted sporting activities
- Dental Treatment and advice overlaps JIA: Provision of education and awareness on Dental Health conditions such as Dental Decay, Periodontal Disease, Dry Mouth, TMJ and better awareness of how Medicines used to treat JIA and its pain and iatrogenic conditions can impact dental health.
- Positive experience of Acupuncture and how it was used as an adjunct to treatment of arthritis
- Goal Setting, Life Mapping and having fun are tools that will bring any individual on any part of their Journey through the tougher aspects of theirs.
- Ask the child- "How do you think?"

## 1.8. Issues/ Barriers within the Current "Transfer" Transition System

- Unrealistic for 16yr olds with risk taking behaviours to transition to adult services
- Transition referral is often interpreted as a "New Patient " referral and this leads a missed opportunity to have a preparatory appointment with the Rheumatology Nurse Specialist and can lead to overwhelm if they had not met the adult service already. Such is the case with satellite services outside St Vincent's who don't have the opportunity to meet the adult team alongside the paediatric team in advance.
- Belief that "Transition " is a key process. It's difficult at 16yrs, an unwritten rule applies that they will continue care until the patient is ready. Ideally after the Leaving Cert is when she would like to see them discharged.
- No up to date data base of what MDT's are available at each Adult Service.
- Poor Communication from Paediatric Services to the JIA Patients on the fact that they are on a 3 stage Transition Process, with no adjunctive documentation/Toolkit which would assist and track same process, which they claim they have, but is not in use and this is down to budgeting
- System failure in the areas of Professional Education-not enough education on JIA amongst Pedestrians, GPs and the MDT members whom they transition to. Hence, as reported by patients who suffered emotional trauma. Teens and adolescents are still learning to care for themselves and may not have the self-management/advocacy skills at an age appropriate time and it can lead to missed appointments and poor management of their disease and medications and often lead to them being lost in the system or drop out because of poor follow up due to professionals not fully understanding or considering these unique issues. In addition, it was suggested that it is important that Rheumatologists both, Paediatric and Adult select "that" GP, Paediatrician MDT and members who have a great interest in Rheumatology so they can direct patients to them for adjunctive management. Better Paperwork/Guidelines to each of these Professionals is needed to communicate correctly the patient's mental, emotional and physical health along with medications.
- Patient Education is inadequate and a homecare plan/toolkit to build readiness for Transition is not available to the patient or to their parents who are their advocates. It will assist with the development of better autonomy, self-management and support "If the Teen/Adolescent does not have a guideline/map of things to be doing for themselves they cannot hope not to be overwhelmed.
- Parent Education, is vital from the beginning to the end of the journey with JIA. As Transition begins education allows them to help support their child through each Transition stage in a positive way. Parenting networks will give support, education and even an odd funny tale along with some hope so that they do not feel isolated in this tough journey.
- Poor Skills Development
- Poor resources i.e. funding, staff and units to actually serve both the Paediatric and Adult Services.
- No "National Transition Workshops"
- No physical Transition Clinic outside of Dublin
- No current links with other Chronic illnesses in Children's groups
- No weekend Transitioning get together like " Epilepsy Star Clinic" in Tallaght
- No Link person appointed to the "National Policy" where Transition is a part of this policy.
- Not enough Psychology support on the MDT, which would build on empowerment, confidence and make children, teens and adolescents more assertive rather than passive.

# ICAN WORKSHOP – SESSION 2

Some of the statements made on the day by participants:

"Trying to navigate the system on your own is hard – often I felt like a neurotic mom."

"Our patients in the waiting room look so healthy – you'd never know how sick they are!"

"Not having connected health records is as difficult for health professionals as it is for patients"

"I was scared when moving from the children's hospital to the adult hospital, and nobody seemed to understand this"

"Patients should be referred to Advanced Nurse Practitioner by rheumatologist to solely manage children's care – this is done in adult services."

"A lot of administration work takes time away from patients: D.A.R.E (Disability Access Route to Education) forms."

"Parents can suffer watching children suffer, and having to administer medications: having to cajole them into accepting treatments"

"I became involved in this focus group because I suffered emotionally. I never had psychology and I want to change that for others"

## 1.9. 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. However, in the US transition was later in life, at college stages.
- **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
- Sexual Health Promotor said aspects of her work can assist better awareness and choices and strengthen the “Middle Stage “of Transition. Working on collaborative program with Jen Stenson: “Teens Taking Charge” - Working with Adolescents and Parents to help them with empowerment to take charge of their health, build their autonomy and work better with their professionals
- U.S. exposed a better Transition Program, yet, like Ireland, still under-serviced: 35 Adult Rheumatologists to 4-5 Paediatric Rheumatologists; Adolescents 18yrs Transferred to them in their first year with a Transition Party and “Cake “and with them for their 3yrs; Fully transfer to Adult Services at 21yrs-had the skill set to take on their medical world; 30% “Attrition Rate”
- YARD Model in Ireland: Transition Process from Crumlin to St Vincent’s Hospital
- “Ready, Steady, Go “ Model discussed and needs a personalised plan with HCP, Parent and Patient- faults as no
- Through the lived experience you get a different child presenting to “Transition “
- Connecting with BSPAR and EULAR required
- Self-Management-for under 11yrs essential
- Adult service by 16yrs with Dr Jenkins and Glenda ( Physio and CCA member) Positive experience

## 1.10. Discussions re: Workshop?

- What would the HCP's like to see at our National Workshop?
  - Combination of Adolescents, Adults
  - Health Professionals, Educational Representative, Sexual Health Educator
  - Food
  - If HCP unavailable, a suggestion of a Video Clip" Welcome to the Weekend" etc.
  - Welcome-Ice Breaker in the form of an activity or a role play of a selected topic as chosen by our next Focus Group, i.e. they could select a role play of a consultant/adolescent chat!!
  - Facilitators who will act as Buddy/Mentor-shown to work with youth (I'm adding-consider mobility of both facilitator/Buddy-know in advance who will be with whom and will we need to cater for mobility issues )
  - World Café Model suggested as a medium to present the topics-time suggested 10-15 mins on each table
  - No sitting Presentation-if so 10 minutes' max as youth zone out
  - Plenty of breaks and more food
  - One participant felt that it was important not to refer to the attendees as "Sick Child/Children
  - Rheumatologist would like Patient Education around "Skills Development" in relation to self-injecting.
  - One participant felt it would be important to include the topic of "Acceptance" and highlight that JIA is a part of your life not your whole life.
  - Patients/Parents would like to see a passport/toolkit to track the" Transition Journey"
  - Patients/Parents want to see a Self-Care aspect to the Workshop focusing on holistic options, diet, dental health, psychology and communication options discussed
  - Design of a Toolkit for the Specialist through the Workshop. If we allow this we must be ready to accept the consequences of it's content
  - Toolkit for the Schools and how they want the school to assist. If we allow this we must be ready to accept the consequences of its content

## 4. Solutions to Challenges

### 1.11. Information (Collaborative Approach)

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

### 1.12. 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

### 1.13. 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

### 1.14. Timelines

- Date for young people's workshop February 2017
- Date for completion of Information Toolkits July 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: September 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.