

1. Overview

This workshop included adolescents and young adult mentors with JIA. The 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. It was also to ask the adolescents what their journey had been to date and to ask them what mattered to them. All participants had a keen interest and passion in the transitioning of care from young person's rheumatology services to adult services.

Date:	11/04/17, Tuesday	Time:	10.00am – 2.30pm
Location:	Maldron Hotel, Oranmore	Facilitated by:	Ms Olive O'Connor
Appointed by:	ICAN; Ms Wendy Costello	Note keeper:	Ms Bernie Ffrench

2. Introduction

1.1. Overview

- Group facilitators introduced themselves and explained what a focus group was: a focus group was to listen to the participants and ask what their journey has been to date, and that the facilitators take in anonymous information with an intention to do something with it - in this case create a "National Transition Workshop". The facilitators introduced themselves and shared their stories and why they wanted to run this focus group.

1.2. 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

1.3. Aims of this Workshop

- An outline of the subjects to be discussed was shared:
 - Sharing the JIA journey with one another
 - Understanding Transition Models – what experiences have adolescents with transition?
 - What age would they like Transition to start?
 - What would adolescents like to see in our National Workshop?

1.4. Participants Present (12 in Total)

- Participants were either adolescents who were diagnosed with varying forms of JIA or young adults who had gone through the journey and would become mentors for young people. Participants ranged in ages from 12 – 30. There were ten females and two males present. Some participants were in primary school, others in secondary school and more in college or in employment.

3. Opening Session

1.5. 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** Parents speaking on behalf of children – not talking to the child, Doctors speaking on behalf of child - disempowering
 - **Employment** Participants had some careers they were interested in following but felt they may not be able to do it because of their conditions (e.g. pilot). This caused concern. One of the adult mentors explained that now more positive experiences employed and protected in her employment working 2 days per week & learning to drive despite her disability
 - **Family Impact** Many did not like the impact JIA had impacted their family
 - **Friendship Impact** This varied – many participants had a small group of friends that understood their condition, others had none at all – some were bullied. “Hard to make friends in the first year.” Growing up with JIA compared themselves to friends and had to learn to pace themselves and listen to their bodies more, “not growing up as you’d like too”. “Friends are great support in primary school” – does this change in secondary school?
 - **Communication** Participants felt that communication was poor and that they should “not have to tell their story over and over”. Some had lots of questions. “What was it? Was it contagious? Would his friends get it? Could he do this or that because of it? Would his friends accept it? What can I do?”
 - **Multiple Conditions and JIA** many participants had multiple conditions but there was no connectivity in the system to join the health professionals together
 - **Listening** Doctors were not listening and hearing it was “all in the head” and “growing pains” was hard.
 - **Medications** This was an issue for all participants - “Hates Methotrexate, gets angry with its effects. Also on Anakinera daily injection, Plaquenil and steroids high dose reducing to low dose. Has to keep “Anakinera” in an upright position and in the fridge or cool pack at a certain temperature and this affects sleep overs and trips away. Travelling through airports can attract security. “Medications don’t really help - Humeria injection is hard and has to have her G.P. to do it.”
 - **Adult Services** Putting children into an adult service/unit/outpatient department is daunting
 - **Verbal perceptions:** Statements like “it’s an old person’s disease”
 - **Emotional Impact** (Fear of change re: transition, control issues, phobias)
 - **Misdiagnosis** Not getting diagnosed early has long lasting physical and emotional impact
 - **Community/ Charity Services:** Participant didn’t find iCAN until 18yrs old, would have loved to know about it earlier. Other participants were told to “find” adult rheumatologists – no guides given. Finding the iCAN Leaflet in Crumlin was a positive experience for some participants. Others felt iCAN was a great place to talk and discuss the journey and that they got great support. They relate well to iCAN “it’s the common denominator that helps the journey.”
 - **Psychology Support:** Should be available immediately from onset of conditions
 - **Health Records:** Should be to hand – participants tired of having to repeat “stories”
 - **Understanding Stages/Changes of Care:** Many participants were unaware they were in Transition and had no tools to prepare or help through it. In addition, he feels there is a lack of time spent with the team. He would like to have more independence and thinks this is important.

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- **Transition:** Participants varied on transition of care; some did have positive transition from a travel viewpoint and time saving, others didn't know they were going through it and more felt they were "pushed out".
- **Inappropriately Aged Services:** Participants felt teenage clinics were "babyish" and still felt like they were young children – seating, animations on walls etc.
- **Technology & Practical Supports:** "The use of electronic Tablets by the whole school has meant that she doesn't stand out." Orthotics in runners have helped greatly and strap for handwriting has helped.
- **Peer Support:** Two previous students who went through the school, have made it easier for the school to understand and support her. School friends were supportive, sent in cards to the hospital.
- **Physical Issues:** "Tripping before got proper runners and orthotics."
- **Jargon:** "Can't understand the journey - the language used to describe JIA, treatment and meds is not child friendly."
- **Health Professional Support:** O.T. and Physio are a great help especially with resources for the school. Gets help in the Summer from teacher's due to high absentee rate. Doctor fought for her here in Galway when Crumlin were not listening.
- **Explaining Condition:** "Giving a presentation to the school and they "got it" most students cried, but some were confused. Lots of empathy and help from the school friends, even those who didn't really understand it the JIA."
- **Self-Advocacy:** "Confident saying to rheumatologist that the methotrexate makes her feel so bad."
- **Assessments:** The assessment sheets do not get looked at when we fill them in the waiting room prior to our appointments.

4. Experiences from Adolescents View Point

- 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:** Many participants had developed “Needle Phobia”
 - **Impact on Family:** It is not just the child that is impacted by JIA; it affects parents and siblings too
 - **Impact of 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. Some told they were just “growing too fast.” Other participant was diagnosed with SJIA at 10yrs old. Her journey was important and she told how she was 1 week in Tallaght Hospital and 2 weeks in Crumlin with a virus, high temperatures and rashes. Prior to this she had attended her G.P. who said nothing was wrong and bloods tests showed no result. Hard to hear there was nothing wrong when she was so unwell. Day of diagnosis in Crumlin, “Hurricane” and “Didn’t Understand”.
 - **Guilt:** Participants felt guilty for their parents and siblings
 - **Feeling Alone:** Participant had 1st blood test done alone and had needle phobia.
 - **Fears of New Drugs:** One participant was diagnosed with PSA at 12yrs old - no treatment available until 17yrs old - was the 1st of Dr Killeen’s patients to start “Biologics” – a lot of fears with this
 - **Denial:** Some participants in denial and know it’s not the best, but keeps them going. Acceptance is an issue. Not telling themselves that they have it (JIA). Having no symptoms can reinforce denial and the belief that doesn’t have it. Asked one participant if thought medicine was playing a role? Answered “it got him out of a hole”
 - **Independence:** Participants would like to have more independence and feel this is important. “Parents don’t really get it”. “Mum did all the talking.”
 - **Angry:** Annoyed as cannot do all they want as the arthritis impacts it. Some negative experiences of not being able to do what friends can.
 - **Resentment:** Many participants felt resentment: “I wish I was like my friends”. “I feel judged”.
 - **Reminiscing:** Remembers the time before having JIA.
 - **Isolation:** Friends in school told her that “you cannot do much so we don’t want to hang out with you”. Wheelchair episodes lost her more friends in her 1st year of Secondary school. Friends told her that she was “Lucky” and they were “Jealous” that she was getting out of P.E., off school, missing classes and using a tablet. Her friendship journey has been the toughest “not to have that one friend”.

1.6. Statements regarding the Current “Transfer” Transition System

- A better Transition would be that children with JIA would start earlier with bloods, injections and build on those skill sets. Teen clinic should be younger and not just a 5mins appointment. In addition, 3-4 teen clinics should happen before full transfer.
- Had his first “Teen Clinic” yesterday and he attended alone and it felt easier to talk about things he wouldn't ordinarily say in front of his parents. His attitude is that “ I'm grown up now and should start to take responsibility.
- Query- Chaperone issue, he was seen alone with a Reg and later Dr Mc Dermot.
- “Transition was not great” - Thrown out of Crumlin mid-flare. Paediatric Rheumatology did not want to change any treatment until transfer to adult service in Croom. Transferred to Croom in Limerick where the words “Cruel” and “Hated” and “left in limbo” were used. Had to find my own way in the system. Found the transition difficult as in Paeds service the adults made all the decisions and it was never questioned. Better communication needed between the Rheumatologists both sides and involving the adolescent patient.
- Her first teen clinic was at 12yrs old, she was just told and didn't know it was a part of “Transition”.
- Wants to know if there are a certain number of teen clinics to prepare for transfer?
- Adult ward when younger was daunting.

1.7. What should a Transition Clinic look like?

- Free and accessible Wi-Fi
- T.V. with appropriate channels
- Appropriate reading materials
- Own age group present
- Encouragement posters e.g. to sit and do your physio, not information on “Preventing falls” or How to manage your Gout, both posters contained pictures of old people.
- A specific isolation area in case you are in need of such.
- Vending Machines with healthier options.

1.8. How should this be approached?

- Teens/Adolescents didn't know.
- Peer to Peer experience to give information, e.g. the 12yr old still in primary school was given an idea of the “Expectations” and said the following “ in a few years X this and that will happen.
- Approaching transition beginning with “Teen Clinics” should be said in 2-3 appointments before they attend their first Teen clinic.
- Asking of lots of questions was suggested. Prepare with a toolkit and take notes.
- Looking at multiple conditions was suggested.

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Some of the statements made on the day by participants:

"I feel I can't be a child."

"Teen clinics are not age appropriate – they feel babyish"

"It is daunting moving from my children's hospital to an adult's hospital – I feel lonely and scared"

"My friends are sometimes jealous that I miss school because of JIA – they tell me I am lucky"

"I didn't even know I was in the process of transitioning, I was never told."

"Transitioning impacts on the timing of my medications being prescribed".

"I was alone when getting my first bloods done – I have since developed a needle phobia."

"I'm angry that I can't play sports or do normal things with my friends, I resent JIA."

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 5th and 6th class and not first year as this is a time when a lot of new change happens for young.
- **What is required** for transition of care?
Using the School Model apply it to how Transition would fit better with all the other life Transitions.
 - Primary School – using the 5th & 6th class years to adapt to the Rheumatology system and have their 1st Teen Clinic during these years. This suits if diagnosis occurred before or during these years.
 - Secondary School - No Teen Clinic in 1st year, but advised at this stage that they will commence in 2nd year or thereafter.
 - 2nd Year after being prepared, 1st “Teen Clinic” Toolkit/Passport to track and prepare for each clinic. Advice to be given to the parent and JIA patient on what to expect.
 - Ideally 2-3 teen clinics within Crumlin.
 - Middle stage to be done in 3rd, 4th, 5th year building on alternating clinics between Crumlin and the future Adult Rheumatology Hospital.
 - After Leaving Certificate, to include repeat L.C. full transfer to Adult centre. There should be a progress review meeting to assess personal, emotional and social readiness.

1.10. Discussions re: Workshop?

- What would **participants** like to discuss at our National Workshop?
 - Friendship and how to tell Friends about JIA.
 - Spoon Theory Video
 - How to communicate? Sometimes we don't understand. It needs to be better with the professionals and Vice versa with us. What are they saying? “ I'm right, your wrong”.
 - Tools to help us talk to G.P. and other HCP, so that I learn to tell them better how I feel. Understand what our blood tests show?
- How **should** the National Workshop be run?
 - Mixed feelings on having the HCP present, No, as it would feel like a hospital thing. Yes, it would be nice to see them on a social level and to see them in more casual clothes and more relaxed.
 - Who? Norma, Derek and Physiotherapists/Occupational Therapists.
 - Mentors: Aine, Niamh and Jay.
 - Mix the age groups 10-14yrs and 15yrs to 18yrs.
 - Include all immediate family.
 - Topics-Self Care to include Dental, Psychology “Know it's ok not to be ok” idea, mindfulness etc. Tips on footwear/orthotics. Discussions on form filling for D.A.R.E., medical forms and employment.
 - Topic- Self-Management to include Readiness form, needle phobia management, Methotrexate management.
 - Parents Workshop Topics

5. 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

- Work with HCP's and ICAN to help develop a national transition care pathway toolkit for JIA
- Self-Management resources promoted at the point of care

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.

6. Agreed Outputs

1.14. Timelines

- Date for national workshop September 2017
- Date for completion of Information Toolkits July 2017
- Date for completion of Pathway Toolkit August 2017
- Launch all outputs 12th September 2017 – National Awareness Day

7. 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

8. 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
- Youth Mentors

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.