

News Rheum



Edition 6:
Conference Issue
Winter 2019

WORKING TOWARDS BETTER RHEUMATIC AND ARTHRITIS RESEARCH - TOGETHER

Welcome to the sixth *News Rheum* Newsletter! This edition focuses on our 2019 ANNUAL CONFERENCE

On November 1st 2019, patients, clinicians, researchers and charities came together for our annual CAR research conference, focusing on the theme *Transitions*. This conference was supported by sponsorship from Pfizer Ireland and Biogen.



Dr. Ng Chun Ruh at the conference

We hope you enjoy *News Rheum*. If you would like to get involved, please contact us at:

patientvoicearthritis@ucd.ie

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2019 Conference Committee

- ◇ Daire O'Leary
(clinical representative)
- ◇ Emma Dorris
(scientific representative)
- ◇ John Sherwin
(patient representation)
- ◇ Stephanie Skeffington
(patient representative)
- ◇ Susie Donnelly
(social science representative)

A Collaborative Approach to Arthritis



& RMD Research 2019

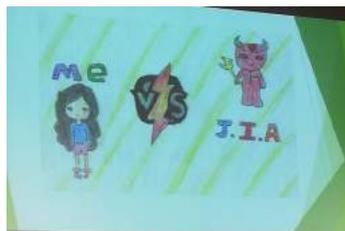


The conference was opened by the conference Chair Dr. Emma Dorris of the UCD School of Medicine. Emma gave an overview of the programme for the day .

She also gave a summary of the Patient Voice in Arthritis Research and reviewed the original aims and targets of the Patient Voice and how they had been acted upon in the last 12 months.

Keynote

The keynote speaker was Wendy Costello. Wendy is a founding member of the Irish Children's Arthritis Network (iCAN) and current Chairperson. Wendy also sits on the PRoS (Paediatric Rheumatology European Society) council where she represents views of ENCA (European Network of Children with Arthritis) associations. Wendy is president of ENCA and a member of the Steering Committee for the UCD Centre for Arthritis Research, in addition to being the first patient advocate to sit on the National Children's Research Centre's Scientific Advisory Committee.



Wendy has two daughters, one of whom was diagnosed with juvenile idiopathic arthritis (JIA) at the age of 3. Wendy's presentation focused on her experience from JIA mum to JIA research partner



Research in Context: The Patient Perspective

In order to put our research into real-life context, each session was chaired by a patient who also gave an overview of their personal experience.

The Keynote session was chaired by Niamh Costello. Niamh has lived with Juvenile Idiopathic Arthritis for the past 17 years. She is currently in her 3rd year studying for a Bachelor of Education student at Mary Immaculate College, Limerick. Niamh is acts as a mentor for iCAN and is also a member of the youth panel for the Teens Taking Charge research programme in association with NUI Galway.

Niamh eloquently highlighted the burden of growing up with an invisible illness and the importance of peer-support.

Session 2: Transitions



Research in Context: The Patient Perspective

Jacqui Browne is a member of the Disability Advisory Committee of the Irish Human Rights and Equality Commission, with over 30 years of experience as a disability equality activist and consultant. Jacquie is also actively involved as a patient advocate in IPPOSI and is a EU-PATI Fellow.

Jacqui highlighted the importance of language and how it can either empower, or disempower. She also discussed the life-course of chronic illness.



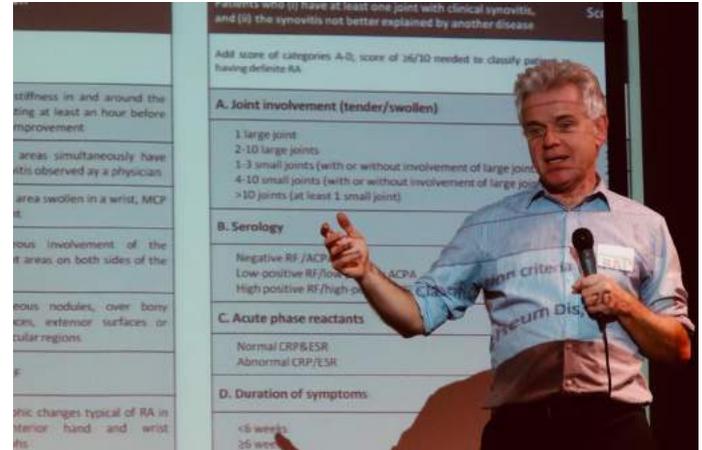
The Psychology of transitioning to diagnosis

Dr. Damien Lowry grew up in a family where sign language was the first language of the home. His only sibling has a rare communication disorder which influenced Damien's interest in the human sciences. Damien now works as a clinical

psychologist in the Mater Misericordiae University Hospital since 2004 where he sees patients across multiple departments who have varying psychological needs.



Transition from Traditional to Precision & Personalized Medicine



Prof. Gerry Wilson is a consultant rheumatologist & Arthritis Ireland/UCD Chair of Rheumatology where he leads the UCD Centre for Arthritis Research. His research aims to discover how inflammation is linked to tissue damage in rheumatoid arthritis; to discover markers of response to therapy; & to determine the genetic causes of rare rheumatic conditions.

Gerry discussed the importance of both our genes and our environment in our risk of disease, and how the interaction of both genes and environment is an important research area to help us treat a person on an individual basis.



Find out more about research:

<http://www.ucd.ie/car/research/>

Session 3: Research Snapshots

Research Summaries from Early Career Researchers

Biomedical Research

Dr. Niamh Morgan



Niamh is a cell and molecular biologist with an interest in rare disease. Niamh is now a postdoctoral research scientist in the UCD Centre for Arthritis Research. Her work focuses on identifying the genetic cause of a rare auto-inflammatory condition, mainly involving childhood-onset chronic oral and genital ulcers, that has been identified in a number of Irish families. The goal of her research is to improve diagnosis and treatment for patients living with this disease.

Niamh's research is funded by the National Children's Research Centre, supported by the Children's Medical & Research Foundation

Physiotherapy Research

Dr. Laura Mackey



Laura graduated from University College Dublin in 2013 with a honours degree in Physiotherapy. Her undergraduate and clinical experiences led her to embark on a research project that examined the role of health literacy in chronic pain outcomes. She completed her PhD in 2016 and then continued working in research, this time as a post doctoral researcher exploring the role of Connected Health technologies for managing chronic diseases .

Research Methods

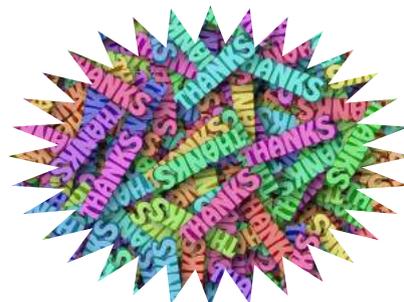
James Maccarthy



James is currently studying Business and Biotechnology in the Michael Smurfit Graduate Business School at UCD. During his undergraduate degree in Biomedical Science he was awarded a Summer Research Scholarship from the Health Research Board of Ireland. Working in the UCD Centre for Arthritis Ireland, James was part of the team that developed and validated a two-step strategic tool to facilitate the successful and efficient integration of Public Patient Involvement (PPI) in basic and pre-clinical research.

These tools are open source and available at <https://doi.org/10.1371/journal.pone.0216600>

Conference Sponsors



A huge thank you to our conference sponsors Biogen and Pfizer Ireland. This sponsorship is critical to the running of our events and allows us to keep our conference free and open to the public.

Go raibh maith agaibh

Workshop on Research Priorities for Arthritis and RMD in Ireland

Research priority setting is a collective activity for deciding which unknowns are most worth trying to understand through research. Unknowns may be problems to be understood, solutions to be developed or new approaches to be tested.

Research prioritisation is aimed at reducing bias in the research agenda. On this occasion, we are carrying out the research prioritisation in association with Arthritis Ireland. Arthritis Ireland will consider these research priorities when deciding what research to fund in the future.

The whole process of prioritisation takes about a year. We want to hear from all stakeholders; in other words, we want everyone who is interested in, or been affected by, arthritis to have their say. This workshop is **Phase 1** and designed to decide the scope of the prioritisation, that is, what should be included or not. **Phase 2** will be an online survey, open to all, to gather the questions you think should be answered about arthritis research. **Phase 3** will be analysis of those questions to filter out those that have previously been answered and those that are not within scope. **Phase 4** will be a multi-stakeholder workshop to critically analysis the remaining questions and create a prioritisation “long list” of 25-40 questions. **Phase 5** will be a second online survey, open to all, in which you will be invited to rank the long list of questions.

The project team: Dr. Emma Dorris (UCD); Dr. Louise Larkin (UL); Prof. Norelee Kennedy (UL); Stacey Grealis; Kar-men Kegl; Stephanie Skeffington.

Clarity in Research Medal

Communication is important for good research. Whereas researchers are often taught the highly specific skills required for scientific writing, less frequently are they taught how to explain their research to the public.

Being able to explain research in plain English is an important skill for both engaging the public, but also for encouraging multi-disciplinary research.

Plain English research summaries are important to increase transparency and openness in research. The public fund research through charities, and through both national and international funding. Research is a public good and researchers have a duty to inform the public about it. Plain English summaries can help members of the public, health professionals, policy makers, funders



and the media keep up to date about research.

The Clarity in Research Medal was judged entirely by a public panel of three were people living with a different type of RMD.

Researchers gave a three minute pitch of their research poster to the judging panel.

Researchers were judged on:

- ◆ The layout of the poster
- ◆ The clarity of the 3 min presentation
- ◆ Use of jargon
- ◆ Pitching (was the presentation too simple or complex)
- ◆ Whether it is understandable



The clarity in research medal is sponsored by Pfizer.

Gold Medal Winner

Self-Managing Rheumatoid Arthritis: A Photovoice Study

Susie Donnelly, T Kroll, H Mannan & G Wilson

Rheumatoid arthritis (RA) is a widespread chronic disease affecting about 45,000 people in Ireland. Without proper treatment it is associated with disability and lower life expectancy. People with rheumatoid arthritis often experience debilitating pain and fatigue. It is described as an “invisible illness” because it is difficult for others to understand what the person is going through on a daily basis. This study uses photography to show what it is like to live with RA. We gave people cameras and asked them to take photographs of living with and managing their illness. As a group, we then created a public exhibition to share these personal experiences to family, friends, policy-makers, researchers and health care staff. At the end of the study, we hope to identify the areas of people’s lives that most need support, and recommend solutions.

This project is led by sociologist Dr Susie Donnelly who works with UCD Centre for Arthritis Research and UCD Health Systems. As part of a Patient and Public Involvement (PPI) initiative, a research advisory group composed of people living with RA collaborated on this project.

Funding for this study was awarded from the UCD Wellcome Trust Institutional Strategic Support Fund. The fund is part of a collaboration scheme between medical humanities and social sciences to support projects that explore the patient’s voice in research.



Dr. Susie Donnelly is awarded her gold medal by Grainne O’Leary of Arthritis Ireland and Jacqui Browne (judge)



The photo voice exhibition showcasing the lived experience of rheumatoid arthritis (RA) from this study is entitled *I’m Here But I’m Not*. This exhibition was launched on 28 September 2019 at The Chocolate Factory Arts Centre in Dublin 1.

It has had runs at the Mater Hospital during National Arthritis Week and Mater Hospital Disability Awareness Day.

Silver Medal Winner

Lending an Ear: Teens Taking Charge and iPeer2Peer Online Self-Management to Empower Teens with Arthritis

Judith Burke , H Durand, J Stinson, A Kohut, L Caes, C Heary, B McGuire

What is the problem?

Juvenile Idiopathic Arthritis (JIA) is a chronic illness that can cause young people to experience pain, fatigue and emotional upset. This can make it difficult for those with JIA to see friends and do enjoyable activities.

Why is this important?

Most teens do not learn how to take care of their arthritis on their own or get the help they need to be able to do so. Most teenagers with arthritis have also never met another teen living with arthritis. This is where online programmes and peer mentoring can help.

How was the programme made?

Canadian researchers developed “Teens Taking Charge” and “iPeer2Peer” to help teens learn to make decisions about their health, meet and be inspired by other young people living with arthritis. Teens in Canada who have gone through the Teens Taking Charge and iPeer2Peer programmes showed improvements in their ability to manage symptoms, understand arthritis and reduce pain. Our research team worked with Irish teenagers living with arthritis, their parents and health care professionals, using individual and focus group interviews, which revealed their interest in both programmes.

What are we doing?

We are testing whether combining iPeer2Peer with an Irish version of Teens Taking Charge will help teens take better care of their arthritis. Any teen with JIA aged 12 – 18 years can take part. Teens will be randomly given a place in one of three groups: 1) Teens Taking Charge 2) Teens Taking Charge & iPeer2Peer or 3) Treatment as usual. Teens that are given the Teens Taking Charge programme will use it over 12 weeks. Teens in the Teens Taking Charge & iPeer2Peer group will be matched with and have weekly Skype calls with a young adult who also has JIA. The overall goal of this combined programme is to improve the quality of life of teenagers with arthritis in Ireland.

What is next?

We are now recruiting 60 pairs of teens and parents with the help of ICAN Ireland, Arthritis Ireland and Children Health Ireland at Crumlin & Temple Street .



Grainne O’Leary and Karmen Kegl (judge) present Judith Burke (NUI Galway) with her silver medal

Silver Medal Winner

Genetics of Rare Diseases: Familial Mucocutaneous Ulceration

Niamh Morgan, E Dorris, E Cummins, F Adeeb, C Taylor, S Savic, OG Killeen, A Fraser, G Wilson

All plants and animals have an innate immune system which acts as a rapid defense mechanism. This system is the first responder to threats, such as infections caused by pathogens or 'germs' like viruses and bacteria. In response to a pathogen, inflammatory signals are released in the infected area which prepares the body to fight the infection. People who have auto-inflammatory conditions commonly experience episodes of unprovoked inflammation that can affect one or multiple organs in the body. These conditions can be caused by a mutation (change) in a gene (part of their DNA) that controls their innate immune system. In patients with an auto-inflammatory condition, the body acts as if an infection were present, even when there is none. Although many of these auto-inflammatory conditions are very severe, they are often very responsive to new anti-inflammatory medicines. These medicines work by blocking the signals that trigger inflammation in our bodies. Identifying the genetic cause (i.e. mutations in patient DNA) of these conditions can help doctors choose the best treatment for patients. Behçet's Disease (BD) is an auto-inflammatory condition where patients' symptoms include ulcers in the mouth or genitals, inflammation in the eye, rashes and, less commonly, inflammation of the bowels, large blood vessels and the brain. It is believed to be caused by a combination of a large number of changes in the DNA

sequence, each contributing small but accumulative effects, and unknown environmental exposure(s). A BD-like illness, affecting both adults and children, has been found in a number of unrelated families in different parts of the world. In these families, changes were discovered in important genes that control inflammation. We have identified five Irish families with a similar BD-like illness. One of these families, a large three generation family with four affected individuals, was first selected for analysis of



Grainne O'Leary, Karmen Kegl & Niamh Morgan (UCD)

their DNA. Over 19,000 genes in their DNA were analysed and it was found that all affected family members had the same mutation in one of the important genes that controls inflammation. The mutation prevents the gene from functioning properly and as a result, patients experience frequent episodes of inflammation and ulcers. In the next part of the study we will perform DNA analysis to find the

mutations causing disease in the other four families. We will also perform experiments in the laboratory, some of which will study the blood cells of affected and unaffected family members, to understand how the identified mutations can disrupt the normal processes that the genes are involved in. Importantly, our research will focus on uncovering evidence that allows doctors to choose the most appropriate treatment for each patient. This will lead to earlier and better disease management, consequently preventing bodily damage and improving the quality of life for the affected patients.

All Conference Abstracts

Two Is Better Than One

[Ng Chun Ruh](#) & *G Wilson*

Introduction:

Rheumatoid arthritis is a chronic autoimmune joint disease that if left untreated will lead to great functional impairment and increase morbidity and mortality. To fight with this chronic disease can be difficult without a strong support network. No man is an island. The idea for this study is to assess the knowledge and understanding of disease amongst spouse caregivers of patients with moderate to severe rheumatoid arthritis and to correlate the knowledge of caregivers to patient-reported survey of patient health.

Method: questionnaire or interview

Objective:

The design of the study is to interview about 50 spouse caregivers of patients with moderate to severe and active rheumatoid arthritis, who either biologic naïve or biologic experienced and then survey their perceptions of disease and its management through questionnaire. The questionnaire will cover diagnosis, treatment, lifestyle with rheumatoid arthritis and the caregivers support methods.

The severity of disease will be assessed by rheumatologist via Rheumatoid Arthritis Severity Scale and DAS 28 Disease Activity Score.

Spouse caregivers will be given a modified 'patient knowledge questionnaire' to assess their knowledge about diagnosis, symptoms, treatment, side effect of drugs and prognosis of the disease.

To assess any association between caregivers knowledge to patients functional and quality of life via SF 36 questionnaire.

Conclusion:

A discussion group can be organised by rheumatology team routinely with the aims of sharing experience amongst caregivers especially spouse and spouse support to fight with chronic disease is of upmost importance .



Ng Chun Ruh is a visiting doctor and rheumatology trainee based in UCD and the Mater Hospital

The Experience of Young Irish Mentors Supporting Adolescents with Juvenile Idiopathic Arthritis: A Qualitative Study

[Hannah Durand](#), N Sweeney, J Burke, C Heary, B McGuire & the Lending an Ear Peer Mentors

What is the problem?

Living with arthritis as a young person can be challenging. Arthritis can cause pain, fatigue and emotional upset. This can make dealing with other things (like balancing school, hobbies, family, friends, and so on) even more difficult. Many teens struggle to learn how to take care of their arthritis on their own, or find it hard to get the help they need to do so. Having a mentor who has had similar experiences and learned to cope with their arthritis can help. Lots of research has shown that having a mentor can help young people to cope with their disease, but very little research has looked at the impact of peer mentoring on the mentors. We wanted to find out more about the experience of being a mentor to another young person living with arthritis.

What did we do?

This study is part of the Lending an Ear Project. Lending an Ear is an online resource for teens living with arthritis in Ireland. As part of the project, teenagers with arthritis are matched with a peer mentor who guides them through the online programme via weekly Skype calls.

The mentors are all young adults who were diagnosed with arthritis in childhood and have learned to manage their disease. For this study, we interviewed four peer mentors before and after they were matched with their first mentee. Then we analysed the interviews for common subjects and themes.

What did we find?

Peer mentors provide a unique and constructive kind of support to young people living with arthritis. The shared experience of living with arthritis was important for building connections between mentors and mentees, but having things in common other than arthritis was equally important. The mentoring process affected mentors emotionally in both positive and negative ways. Mentors found the experience to be rewarding and beneficial, but also challenging.

What do we do next?

We can use this information to improve our peer mentoring programmes and to prepare mentors for the realities of providing peer support.



Judith Burke with her colleague Dr. Hannah Durand from the Centre for Pain Research at NUI Galway

Do we know how to treat post-streptococcal reactive arthritis?

[Yavani Kulasingham](#)

INTRODUCTION

Streptococcus can cause different infections. Sometimes people get inflamed joints after an infection with streptococcus, people get inflamed or painful, swollen joints. This is called post-streptococcal reactive arthritis (PSRA). Very occasionally people also get inflamed in more places, including the heart valves which is called rheumatic fever (RF). It is not clear whether PSRA is a mild form of RF. I want to see if the research so far tells us that PSRA and RF are the same disease or different diseases. I also want to see if it is clear how exactly PSRA should be treated or if we need to do more research to work this out.

METHODS

I performed a literature review which means I looked for papers which have something to do with these two diseases. I did this by searching in some databases called PubMed, Cochrane Library, Google Search. I used the words “rheumatic fever” and “post-streptococcal reactive arthritis” which were published between 1999 and 2019. I looked at papers which clearly defined one or both diseases. I looked to see where in the

world the diseases happen, who they affect, how patients appear when sick, how they are diagnosed and particularly how they are treated.

RESULTS

RF and PSRA present differently. RF typically presents at 12 years of age, whereas PSRA occurs between 8-14 and 21-37 years. The inflamed, painful or swollen joints in RF last 2-3

weeks but in PSRA last for 7-10 days. Patients with RF respond to antibiotic treatment better than patients with PSRA. It is worth using preventative antibiotics in RF. The evidence for treating patients with PSRA with longer term or preventative antibiotics is not strong.

CONCLUSION

The research so far tell us we should see rheumatic fever and post-streptococcal reactive arthritis as separate diseases. However, it is not clear how PSRA should be treated. There is a need to do more

research so that we can come up with the best way of treating patients with PSRA.



Yavani Kulasingham, medical student at the Royal College of Surgeons in Ireland (RCSI) with Dr. Daire O'Leary (RCSI, UCD and CHI Crumlin).

Improving Transition Services in Ireland: What are the Barriers to Success?

Jayne MacMahon, Y Owen, N Oldenburg & OG Killeen

Introduction:

Transition is an important concept in the management of young people and adolescents (YPA) with long term or chronic illness. It refers to the planned move of a YPA from their paediatric health care provider across to adult services. The importance of a planned, successful transition has been highlighted in recent years. Multiple studies have showed that a poor transition can lead to poor patient adherence, outpatient attendance and overall decline in patient outcomes. In order to develop a more structured transition programme, the key areas of need, from the point of view of YPA and health care workers, should be identified.

Aim:

To evaluate health care workers perception of the current transition process in Ireland and to identify areas of need and concern.

Methods:

An 18 question survey was developed. This was distributed amongst health care workers in both the adult and paediatric services via survey monkey. The responses were then analysed using Microsoft Excel.

Results:

The survey had 143 responders in total and an average of 141 responders per question (range 136-143). 78% worked in a paediatric

healthcare, and 57% of those reported working in a tertiary care setting. 70% were directly involved in the transfer of YPA from paediatric to adult services. A structured transition programme was felt to be 'very important' by 92% of responders, with the majority (87%) suggesting between 12 and 16 years as the most appropriate ages to start this process. Notably, 73% felt that Irish YPA were inadequately prepared for the move to adult services. Poor access to adult services, lack of resources and lack of communication between paediatric and adult services were highlighted as the biggest barriers to a successful transition.

Conclusion:

This study identified some of the main barriers to a successful transition, from the point of view of health care workers. The need for a structured transition programme, along with guidelines and increased resources was particularly highlighted.

Did you Know?



We had submissions from undergraduate to postdoctoral level;

From research institutions all across Ireland;

Research was focused on clinical, biomedical, sociology, psychology and communications research

Patient Information for Osteoarthritis

[Kieran Murray](#), [T Murray](#), [A O'Rourke](#), [C Low](#), [DJ Veale](#)

Background

Osteoarthritis (OA) is the most common cause of disability in over 65s. Different treatments include physiotherapy, medications and surgery.

Most patients now look online for health information but are unlikely to search more than 25 pages. Patient health information should be written at a 12-14 year old reading level. For many diseases, online patient information is at university level. The readability (ease of reading something) of online OA information has never been tested. In 2003, online OA information was "poor" quality.

The goals of this study were to check the readability and quality of current online OA patient information.

Methods

"Osteoarthritis" was searched across the three most popular English language search engines (Google, Bing and Yahoo!) and the first 25 websites from each search carefully analysed. Repeated or non-text pages, websites with paid adverts and unreachable websites (for example

behind a paywall) were left out of the study. Readability was checked with three scoring systems used in prior studies (Flesch Reading Ease Score, Flesch-Kincaid Grade Level, and Gunning-Fog Index). Website quality was also scored using systems from prior studies (the Journal of the American Medical Association (JAMA) criteria and the DISCERN criteria. Age of content, maker of content, content author and were noted. Each website was checked for HONcode approval (recommended by the Health On the Net Foundation).

Results

There were 37 different websites suitable for the study. Average readability varied from a 12-17 year old level. Only 1 (2.7%) website met all four JAMA criteria. Average DISCERN quality was "fair," better than in 2003. 16/37 (43%) websites had HONcode certificates. These websites were better quality.

Conclusions

Online OA patient information was equal to or harder to read than recommendations. The information quality is fair, better than in 2003. HONcode approved websites are better quality and should be recommended.



Dr. Kieran Murray, St. Vincent's University Hospital and UCD

Arthritis & Infection

[Kieran Murray](#), *C Low, A O'Rourke, F Young, I Callanan, Eoin Feeney, DJ Veale*

Introduction

Influenza (flu) kills up to 600,000 people yearly. Streptococcus pneumonia is the most common cause of chest and brain infections. Some types of arthritis (like rheumatoid and psoriatic arthritis) and their medications increase infection risk. These patients should get flu vaccine yearly and pneumonia vaccine every five years.

Study goals

- 1). Find out rates for flu and pneumonia vaccines
- 2). Find out why patients not vaccinated
- 3). Find out which patients likely to be vaccinated
- 4). Improve vaccination rates

Methods

In 2017, arthritis outpatients filled out a nameless survey with information on vaccines and 23 questions (age, education, medical problems, medications, vaccines and smart phone access). All patients on arthritis medications leaving them open to infection were included.

At the same time, staff were taught about vaccines. We began using an "Arthritis and Infection Worksheet" and patient and general practitioner (GP) letters listing vaccines needed. In 2018, we re-checked the clinic for improvements.

Results

There were 425 patients in the study. About three quarters were women (74%) and had rheumatoid arthritis (72.6%). 45.6% were over 59 years old. Between 2017-

2018, vaccination rates increased for pneumonia (41% to 47.2%) and flu (61.8% to 62.1%). The most common reason for non-vaccination was not knowing they were needed. GPs gave 83.7% of vaccines, with 3.6% given in hospital. Patients up-to-date for pneumonia vaccine were 9 times more likely to be up-to-date for flu vaccine. Older people (aged over 79 years were 42 times more likely than under 40), those on injectable medications (3 times) and those up-to-date for flu vaccine (9 times) were more likely to be up-to-date for the pneumonia vaccine. 70% of patients had smart phone access.

Conclusions

This study showed low numbers of patients getting vaccines and little benefit from our changes. Phone reminders and offering vaccines in clinic may improve this.

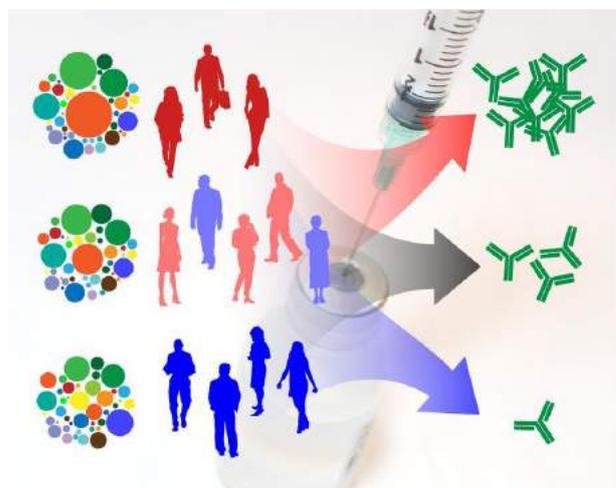


Image Credit: National Institute of Allergy and Infectious Diseases, National Institutes of Health

Managing Chronic Pain: A Psychologist's Guide

Elisabetta Palombella & J Gilmartin

Background It is estimated that there are over 1000 children under 16 years old in Ireland with Juvenile Idiopathic Arthritis (JIA). Many children with JIA suffer with chronic pain. Chronic pain is a pain which is continuous, long term and that persists for more than 12 weeks. Chronic pain has a negative impact on children's quality of life and in some cases causes sleep difficulties, low mood, social isolation and school absenteeism. The role of Psychology within the Multidisciplinary Team is to provide support, acceptance and coping strategies to JIA patients presenting with chronic pain.

Aim and Method The majority of JIA patients who live outside the Dublin catchment area are referred to Local Services for the management of their symptoms. However, due to lack of knowledge on the difficulties experienced by children and adolescents with JIA sometimes patients are referred back to CHI. We designed a leaflet with the aim to provide useful information and to support Psychologists in the Community on common issues experienced by children and adolescents suffering with chronic pain. The leaflet describes the impact of chronic pain on the child and their family; children with chronic pain often have unhelpful beliefs about

their ability to manage pain. The leaflet illustrates some strategies that can be used to help children and adolescents to reduce this unhelpful thinking and empower patients to control their pain. The leaflet includes information on the usefulness of Cognitive Behavioural Therapy and also provides a list of useful resources and links that patients can access to manage chronic pain.



A crowd listens to Elisabetta Palombella, Counselling Psychologist at CHI Crumlin, and her colleague and research student Josephine Gilmartin (DCU) explaining their research

Results It is anticipated that this leaflet will help Psychologists working in the Community to get a better understanding of the impact of chronic pain on children's emotional wellbeing and their quality of life.

It is hoped that psychological intervention in the management of chronic pain in children will result in increased self-management of pain, reduce pain-related disability and reduce emotional distress.

Exploring Motivations For Participation & Non-Participation In Chronic Disease Self-Management Programmes Among People With Arthritis In Ireland

[Joanne Tan Huey Min](#) & *S Donnelly*

Chronic diseases are recognized as a major component of health service activity and expenditure [1]. "The Chronic Disease Self-Management Program (CDSMP)" developed by Stanford University is used to control chronic diseases [2]. In Ireland, courses based on this model are offered by the HSE and Arthritis Ireland.

The aim of this research is to explore motivations for participation in CDSMP, particularly in relation to arthritis. It will investigate who takes parts - or does not take part in these programmes and whys.

A web-based questionnaire on arthritis patient's experience of CDSMP in Dublin was conducted. The participants included people of ages between 18 to 60 years and above whom attended and did not attend CDSMP. The research design used Public and Patient Involvement (PPI) where the student researcher collaborated with patients to gain feedback to ensure that the questionnaire was relevant, meaningful and accessible for patients.

In terms of respondents who had taken part in a CDSMP, exercise information was reported as the most useful and important things learnt during the programme. Indeed, 44 per cent (n=20) of participants self-reported that they increased in exercise and physical activity after attending the programme. In terms of respond-

ents who had never taken part in a CDSMP, the survey found 49%(n=46) of participants are not aware of CDSMP and not available in their area. The study was not well-represented for arthritis population in Ireland. It was only catered to participants who are familiar with using social media as a media for communication.

Joanne carried out her research as part of the



UCD School of Medicine Summer Student Research Awards Programme 2019

References:

1. Chronic Conditions Working Group. Health Service Executive (HSE) [Internet]. 2015 December [cited 2019 Aug 4];57:13-14. Available from: <https://www.hse.ie/eng/health/hl/selfmanagement/hse-self-management-support-final-document1.pdf>
2. Lorig. Chronic Disease Self-Management Program: insights from the eye of the storm. 2015;253(2):1-3.

Spreading the Word: Using Stakeholder Engagement for Effective Approaches to Increasing Awareness of Inflammatory Arthritis of Down Syndrome

[Amirah Alzaki](#), [A McNiffe](#), [A Valente](#) & [E Dorris](#)

Children with Down syndrome (DS) are at increased risk of developing inflammatory arthritis. Inflammatory arthritis of DS (IADS) is a clinically distinct form of arthritis with a higher prevalence rate (20 per 1000) compared to the rate of juvenile idiopathic arthritis within the general

population (1 per 1000) 1,2. IADS is often under-reported and diagnosis is often greatly delayed. As a result, children with IADS present with significant joint damage and disability at diagnosis¹.

The aim of this research was to increase knowledge translation of the novel findings of recent research to the gatekeepers of early intervention: primary caregivers, carers, parents and people with DS. We worked with two parents of children with IADS to discuss challenges and identify which communication tools would be most useful to raise awareness of those key challenges of IADS. Involvement partners were part of the project from conception to dissemination. In response, a

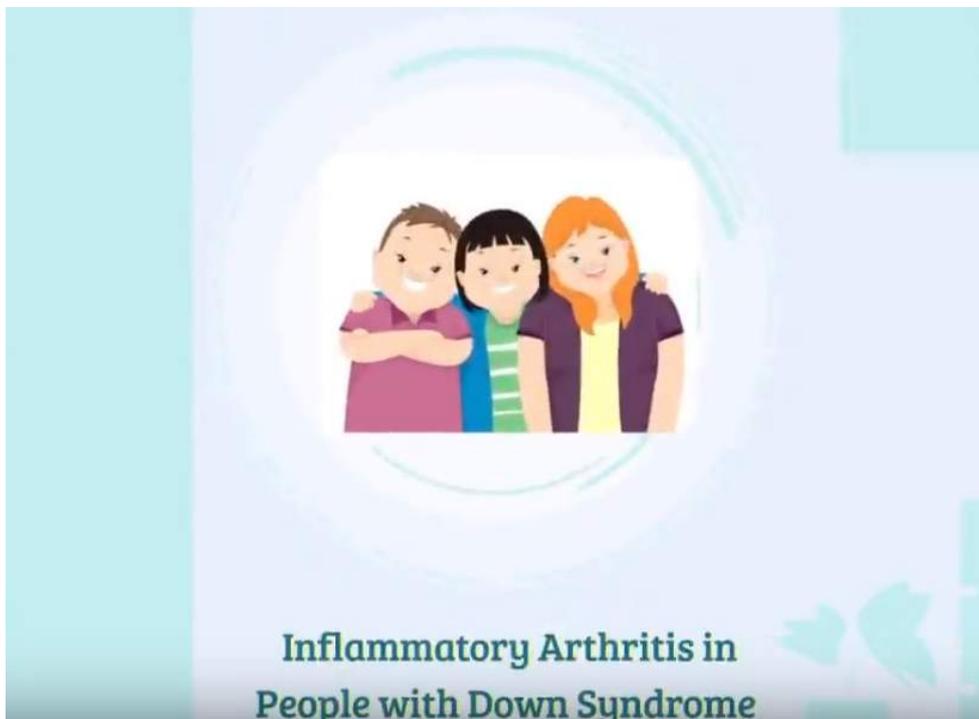
video and an information brochure were designed. For both resources, we used an iterative design process with multiple review rounds from both the target audiences and the clinical professionals. Production of an information animation video designed for social media circulation,

primarily aimed at people with and carers of those at risk of IADS. Also, we created an information brochure targeted to primary care professionals, patients, their families, ter-

tiary care professionals who do not know IADS well, the R&D community and the general population. Overall, parents greatly favoured an easily sharable resource (the video) and a visual brochure with easy to remember facts.

Reference

1. Foley C, Deely D, MacDermott E, Killeen O. RMD Open. 2019;5(1):e000890.



Amirah worked with parents of Children with Down Syndrome Associated Arthritis to create an awareness video. You can watch it on YouTube at www.youtube.com/watch?v=JMIrUwN6_qs&t=10s or search "Down Syndrome Arthritis UCD"

Cellfies: Images of Research Christmas Edition

By John Burns



Algae in Red and Bacteria in Green

Dr. John Burns is a senior research scientist at the Bigelow Laboratory for Ocean Sciences in Maine, USA. John studies a green algae called *Cymbomonas*. *Cymbomonas* is an unusual little algae because it has the trait of cellular eating (called phagocytosis) which is very unusual in any plant or green alga. *Cymbomonas* is old, really old, in fact it belongs to one of the oldest algal groups. This single-celled alga usually survives by feeding on sunlight (photosynthesis), as you would expect of a plant or green alga. However, if it has to survive under low light levels it took to eating bacteria. John's research is trying to figure out how it can do this.

*"This experiment is trying to catch the little alga in the act of feeding. The alga (seen in red in the picture) is a relative of plants that eats bacteria. We think that is an ancient trait of algae and plants. So, we know it eats, but we're not sure how. One way to learn that would be to watch as the alga ingests something bright and visible. So I tried feeding the alga (*Cymbomonas*) some *E. coli* bacteria that are expressing the fluorescent protein GFP (green). I did not see any evidence that the algae were eating these bacteria (they are kind of notoriously picky eaters, unfortunately). But after a while the bacteria fell into clumps . . . I took a few pictures to mess around because I thought they looked nice. Sometimes that's needed with experiments that don't pan out! I thought this one looked like a Christmas tree"*

John is a collaborator with one of our scientists at UCD Centre for Arthritis Research. Another example of the diverse and varied people and research we work with and learn from.

You can follow John on twitter at @burnsajohn



Thank you for your support throughout 2019. We look forward to building an even stronger community working towards improving the lives of those living with arthritis and rheumatic disease in 2020.

From everyone at News Rheum and the UCD Centre for Arthritis Research we wish you and yours a very Merry Christmas and a peaceful and prosperous 2020.

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