OUTCOMES THAT MATTER TO PEOPLE LIVING WITH INFLAMMATORY ARTHRITIS: A GLOBAL STANDARD SETTING APPROACH FOR A UNIVERSAL CORE CONSORTIUM FOR HEALTH OUTCOME MEASUREMENT (ICHOM) WORKING GROUP FOR INFLAMMATORY ARTHRITIS

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Background: Value-based health care (VBHC) is a framework for improving efficiency of healthcare in which competition on value for patients is the central concept. Public reporting of patient outcomes by healthcare providers is proposed as a mechanism that will accelerate identification and adoption of innovations that increase value, through shared learning and sparking competition on outcomes that matter to patients. A key barrier to the implementation of VBHC in inflammatory arthritis (IA) is the absence of a universally accepted set of patient outcomes and risk adjustment variables that are appropriate and feasible to implement in different healthcare systems worldwide.

Methods: The International Consortium for Health Outcomes Measurement (ICHOM) assembled a multidisciplinary international working group (WG), consisting of 24 experts, including six patient representatives, to develop a standard set of patient-centred outcomes for IA. The process followed a structured approach using a modified Delphi process to reach consensus on (1) medical conditions to be covered by the set, (2) outcome domains, (3) outcome measures, (4) case mix variables and definitions. Each step was supported by systematic literature reviews and consultation of (external) experts on the topic under consideration.

Results: The WG decided to include rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis and juvenile idiopathic arthritis in the IA Standard Set. Twenty-four outcome domains were initially identified in the 130 randomised trial reports and 28 qualitative studies that were found in the systematic literature reviews. Ultimately, pain, fatigue, activity limitations, overall physical and mental wellbeing, work/school/household activity and productivity, inflammatory disease activity including therapeutic response (i.e. has the patient achieved the treatment target?), and serious adverse events were included. The measurement properties of 21 patient-reported outcome measures were assessed for all of the included domains. 20 of these were linked to an item response theory-based common reporting metric. This allows users of the ICHOM IA set to choose their preferred instrument while allowing comparison of outcomes. A number of risk adjustment variables and time points for collection were recommended to allow global benchmarking.

Conclusions: We present the ICHOM standard set of outcomes for Inflammatory Arthritis, that we encourage providers of care to implement to facilitate global comparison of outcome data and stimulate shared learning.

Disclosure of Interest: None declared


FRIDAY, 15 JUNE 2018

Innovative treatments for a better quality of life

LOVE YOUR HEART, AN ONLINE, INTERACTIVE CARDIOVASCULAR RISK ASSESSMENT PROGRAMME FOR PEOPLE WITH RA/A

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Background: Having RA doubles the risk of most heart problems, including heart attack, stroke and atherosclerosis — the build-up of fat, cholesterol and cellular debris (plaque) on blood vessel walls. Studies show that approx. 50% of people with RA die prematurely due to cardiovascular disease (CVD) one of the most common co-morbid risks. Many patients and even health professionals are unaware of this leading potentially to poorer long-term outcomes. UK Rheumatologist, Dr. Holly John originally developed and piloted this programme in group face to face format in Dudley which achieved very good results, but the format limited the number of people who could access it and benefit from it. NRAS, with Dr. John’s permission, wanted to make it as widely available as possible to all with RA. Being unaware of these risks means that people with RA can be less likely to address factors, firmly within their own control, such as smoking, exercise, weight and diet.

Objectives: In order to make this programme freely available to all, we had to convert a face to face paper-based programme into an on-line, interactive video which would not only enable us to assess their own personal CVD risks and set goals to mitigate such risks. We have also included within the programme baseline and 6 month follow up assessments to measure intended and actual behaviour change. The overall purpose of the programme is to achieve a healthier heart lifestyle thereby reducing premature mortality due to CVD.

Methods: Using the paper participant manual created for the group programme but working closely with Dr. John and other health professional specialists (exercise, smoking cessation, nutrition) at Dudley as well as patients who had attended the programme, we reviewed with our creative film production team the best way to adapt this to create a really engaging, interactive on-line educational experience which would allow participants to undertake the programme over time whilst working through the goal-setting and evaluation process. 2 days of filming were done in Dudley and Maidenhead at the end of 2016 followed by 12 months’ period of editing, review, some re-filming and software development. The programme piloted with 20 people with RA at the end of 2017 and their feedback has been incorporated. The programme launches in the UK on 14th February, St. Valentine’s Day. Heart-shaped business cards and A4 posters describing the programme with links to register, will be sent to all rheumatology units across the UK in February/March encouraging GPs to refer their patients to Love Your Heart.

Results: Many people have registered interest in this programme and we anticipate a high take up immediately post launch. Numbers who have participated by early June, together with anonymised baseline assessment details including intention to change behaviour will be available by June/EULAR should we be successful in having this abstract accepted.

Conclusions: It is too early to draw any conclusions but we hope that by EULAR 2019 we will have some interesting conclusions to report on. We anticipate that this programme is more likely to encourage patients to make heart healthy lifestyle choices than being advised to ‘exercise, eat healthy, lose weight, stop smoking’ by health professionals during routine clinic appointments.

Acknowledgements: We would like to acknowledge the input and commitment of our technology partner Streaming Well Ltd.

Disclosure of Interest: None declared


BEHAVIOUR CHANGE EXPERIENCES AND NEEDS OF PEOPLE WITH RHEUMATIC DISEASE


Background: Persons with rheumatic diseases have a higher rate of surgery as well as a need of beneficial lifestyle behaviours, in order to control risk factors associated with surgery and disease co-morbidities.

Objectives: The objective was to explore behaviour change experiences and needs of individuals similar to patients undergoing knee and hip surgery.

Methods: A survey was designed with focus on current lifestyle behaviours, experience of behaviour changes; desire to change behaviours; and attitudes and willingness to adopt digital tools in the behaviour change process. The survey was distributed via a web system to 13664 Swedish Rheumatism Association (SRA) members with a rheumatic disease.

Results: 1660 consented to participate of whom a majority were women, 1/2 between 45 and 64 years of age and 1/3 older than 65, where 2/3 had experienced at least surgery and 2/3 of these 2–3 surgeries, with 1/4 concerning knee or hip surgery, 20% had experienced complications. Almost all respondents had access to a smartphone, computer and the internet. The most problematic current behaviour was insufficient physical activity, with less than 1/5 engaging in recommended levels of physical activity/week. 2/3 indicated consumption of risky alcohol consumption. Regarding healthy eating, a large majority ate breakfast daily, 3/4 ate fruits and vegetables daily, and slightly under 1/2 ate fish 2–3 times a week. However, about 2/3 consumed unhealthy foods several times/week, with 1/5 consuming 2 times/day. Accordingly, 2/3 indicated they would like to increase physical activity level and over 1/2 wanted to improve eating habits. 20% wanted to change other behaviours such as weight loss, consumption of sugary foods, and stress management. Fewer than 10% wanted to change their smoking habits and less than 1/20 wanted to change their alcohol habits. A majority had attempted prior behaviour change, 3/4 focused on physical activity, 2/3 on healthy eating, 1/5 on smoking and 1/20 on alcohol. Regarding the duration of the change, it was permanent for 2/3. Among those who succeeded in maintaining the change during a shorter period, 44% succeeded for 3–6 months, 1/20 for 6–12 months and about 1/10 for periods of 1–2 years. Regarding types of support used for implementing behaviour change, 1/3 had no support but only 1/10 found this helpful. Almost half used self-help, 1/5 used social support, 1/5 used professional support, and 1/10 used digital support. Most helpful were self-help, followed by social, professional and digital support, respectively.