

Living with Rheumatoid Arthritis in Cornwall Report on a public patient involvement initiative 2012



Aims

- To find out from people with Rheumatoid Arthritis (RA) in Cornwall how RA affects their ability to participate in all aspects of life including work, social life and leisure.
- To obtain respondents views on how the impact of RA on participation could be reduced.
- To identify patient's research priorities.
- To identify individuals who may be interested in working together to develop this research.

Participation

“Participation” refers to the ability to be involved in all aspects of life and includes physical independence, mobility, occupation, social integration and economic self-sufficiency (Perenboom & Chorus 2003).

Literature Review

A search of the literature relating to RA and participation was carried out using Medline, CINHL, EMBASE and Psychinfo.

Literature reviewed for 3 of the 9 ICF domains: interpersonal interactions and relationships, major life areas and community, social and civic life.

Consultation with people living with RA in Cornwall

- Workshops held in Helston, St Austell and Launceston – 17 women and 6 men attended.
- Interviews at rheumatology clinics at RCHT and St Austell Hospital – 8 women and 2 men interviewed.
- Interviews with 5 clinic staff from RCHT Rheumatology clinic.

Analysis

- The workshop discussions and interviews were recorded and transcribed.
- The transcriptions were analysed using thematic analysis to identify key themes.
- Randomly selected transcriptions analysed by 2 other researchers for validity check.

Key themes

- Employment
- Social support
- Social life and leisure
- Sexual relationships
- Family relationships and social roles
- Pain and fatigue
- Financial impact and access to benefits
- Exercise
- Mobility
- Access to disability aids
- Information needs

“It’s not the end of the world because you’ve got arthritis. It is something you don’t want but it doesn’t have to stop you in your tracks.”

Context of participation in Cornwall

- Cornwall is a large highly rural county.
- Lacks a major urban centre and the main towns are small by national comparison.
- Scattered population with around 47% of people living outside towns with populations greater than 3,000.
- The economy in Cornwall is dominated by retail, public services, tourism and manufacturing and there are a large number of small employers.
- 89% of businesses in Cornwall have less than 10 employees.
- Higher percentage of self-employed than is found nationally.

Priorities for facilitating participation

Transport – the problems

- For people with mobility problems transport in Cornwall can be difficult and expensive.
- Buses that serve rural areas may not have disabled access and the long distances means that using alternative transport such as taxi is costly.
- Using mobility aids such as scooters and walkers can be difficult in villages and rural areas where there may be no or narrow pavements and high kerbs.
- The eligibility criteria for community buses and volunteer cars may exclude younger people with mobility problems.

Priorities for facilitating participation

Transport – suggested solutions

- Make information more widely available on mobility schemes and how to access services such as car assessments and adaptations.
- Creation of area “car pools” of people who have RA or other long term conditions so that people can help one another out with lifts and regular trips.
- Advocate for the expansion of disabled friendly transport facilities in the county

Priorities for facilitating participation

Employment– the problems

- A lack of understanding of rheumatoid arthritis and its effects among employers and fellow employees.
- The barriers to participation in employment in Cornwall may be exacerbated because of the very large number of small employers.
- An unwillingness of employers to make reasonable adjustments.
- Difficulty in find advice on how to make adaptations at work especially if working for smaller businesses which have no occupational health staff.

Priorities for facilitating participation

Employment– suggested solutions

- Run a local information campaign to increase employer's awareness of RA and how to support employees with RA especially targeting smaller employers.
- Provide more information to people with RA on what their employment rights are.
- Provide more guidance for patients on how to make the decision whether to leave work or not because it is difficult to get back into employment once you have left.

Priorities for facilitating participation

Social support – the problems

- The lack of public awareness about Rheumatoid Arthritis: Sometimes hard for family and friends to understand the severity of the disease because with modern treatments people tend not to have joint deformities so there are no visible signs of the disease.
- Lack of peer support for people with RA: Changes in the management and treatment of RA have led to fewer opportunities for patients at the clinic to meet and chat.
- No support groups in Cornwall for people with RA.

Priorities for facilitating participation

Social support– suggested solutions

- Introduction of a "buddy" system at the clinic where newly diagnosed patients could be paired with a patient who had more experience with living with RA.
- As part of the routine system newly diagnosed patients could be invited to attend a meeting for new patients - queries could be answered and could meet other people in a similar situation.
- Form a support group in Cornwall where people could meet others with RA either in person or on-line.
- Hold a series of talks on RA – provides opportunity to learn about particular aspects of RA and to meet others in a structured, purposeful way.

Priorities for facilitating participation

Exercise– the problems

- Uncertainty about how much exercise is safe to do.
- Rationing of help with exercise – limited access to physiotherapists and exercise professionals.
- The cost of exercise e.g. swimming.
- Lack of information on where to access appropriate facilities across the county.

Priorities for facilitating participation

Exercise– suggested solutions

- More information on the kinds of exercises that are appropriate and safe limits to exercise.
- More facilities such as hydrotherapy pools/warm water pools.
- Greater access to hospital gyms.
- Discounts for people with RA and other disabilities e.g. shorter swim slot for half the price.

Priorities for facilitating participation

Disability aids– the problems

- Lack of knowledge about how to access disability aids, what is available and entitlements.
- Uncertainty about the role of occupational therapists and how they can be accessed.
- Cost of non NHS supplied disability aids and how to ensure are fit for purpose.

Patient partners in research

- Respondents were asked whether they would be interested in working with the team at RCHT to develop research projects.
- 5 respondents registered an interest in taking part and in attending a research workshop.

Research priorities

It was agreed that the first priority for research in Cornwall should be how to improve access to exercise for people with RA.

Research

- The RCHT team and the RA patient research group have are working together on 2 grant applications:
- Arthritis Research UK application for an education grant to assess the training needs of community based non-specialist nurses and allied health professionals in relation to the diagnosis and management of arthritis – submitted, awaiting outcome in July 2013.
- HTA application for a project to enhance engagement in Exercise Referral Schemes with a focus on arthritis – initial proposal will be submitted August 2013.

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