

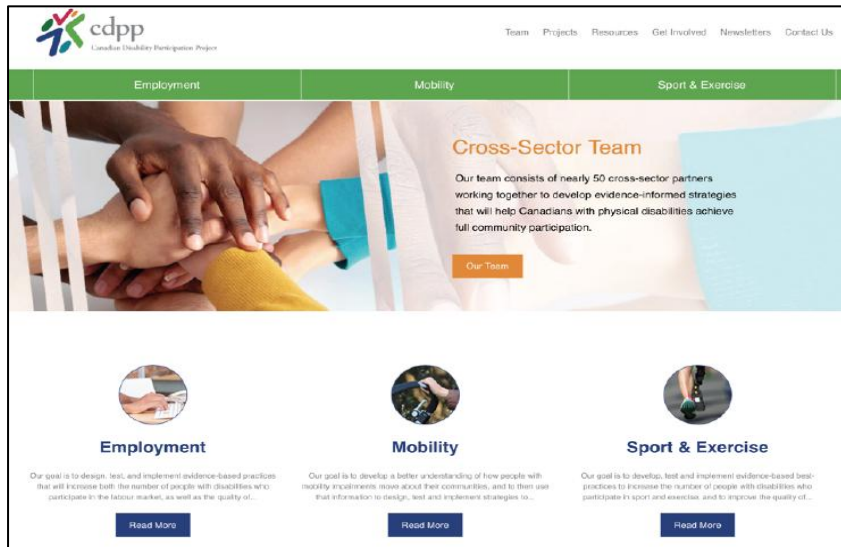
Transitions that matter: Life course differences in the employment of adults with arthritis

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Institute for Work & Health
Plenary, Fall 2016

Canadian Disability Participation Project

www.cdppp.ca



The screenshot shows the CDPP website with a navigation bar (Team, Projects, Resources, Get Involved, Newsletters, Contact Us) and three main content areas: Employment, Mobility, and Sport & Exercise. The central focus is the 'Cross-Sector Team' section, which states: 'Our team consists of nearly 50 cross-sector partners working together to develop evidence-informed strategies that will help Canadians with physical disabilities achieve full community participation.' Below this are three circular icons representing Employment, Mobility, and Sport & Exercise, each with a brief description of their goals and a 'Read More' button.



Arthritis

100+ conditions characterized by inflammation, stiffness, swelling, pain, and fatigue¹

- Chronic, invisible, and episodic
- Involve all joints and internal organs



Common categories of arthritis include¹:

- **Osteoarthritis (OA)** – degenerative joint disease
- **Inflammatory arthritis (IA)** – body's defense system attacks joints (e.g., rheumatoid arthritis, juvenile arthritis)

Snapshot of arthritis in Canada



One of the most common chronic conditions¹

- 1st women; 3rd men

4.6 million Canadian adults report having arthritis ¹

- Number is expected grow to 7.5 million by 2036

56% of those with arthritis are under the age of 65 years

- **Prevalence increases with age²**

59% of Canadians with arthritis report activity limitations¹

- 2x likely than people with other chronic conditions
- 7x more likely than people without chronic conditions

Arthritis work disability in the media

ELLE FASHION BEAUTY CULTURE LIFE & LOVE HOROSCOPES

Where to Get Beyoncé's
Hillary T-Shirt

The Best Books to Read This
November

The 20-Week Abortion Ban
Bind

10 Perfect Shades of
Strawberry Blonde Hair

Zendaya Launches a Fashion
Line

Selena Gomez Will Put Tour on Hold to Work Through Depression and Anxiety from Lupus

"I need to face this head on to ensure I am doing everything possible to be my best..."



MOST POPULAR



Selena Gomez Reemerges for the First

tendons, so much so that I couldn't walk," he said. "It progressively got worse, so I got it checked out."



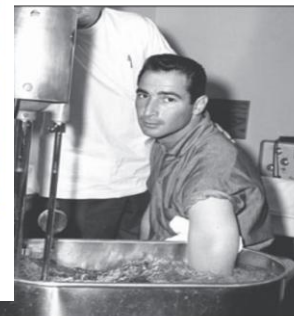
Woods could replace Tiger Woods as world No. 1 this

weekend © Getty Images

Enlarge

right thing and I don't regret one minute of the past 12 years. The only regret is leaving baseball," the 30-year-old pitcher said.

Koufax, whose lightning-fast ball and sweeping curves had befuddled National League batsmen for years, said he had told General Manager E.J. Bavasi just before the season ended that it likely was his last year. He said he informed Bavasi last night he



Associated Press

Sandy Koufax, the brilliant Dodgers left-hander, soaking his arm in a whirlpool after a game in April 1964. Before his retirement after the '66 season, his arthritis progressed to the point where he had to shorten the left sleeves of his coats.

Arthritis and work disability

>25% of working-aged Canadians with arthritis are not in the labour force.¹

An arthritis diagnosis can result in immediate and sustained loss in employment.²

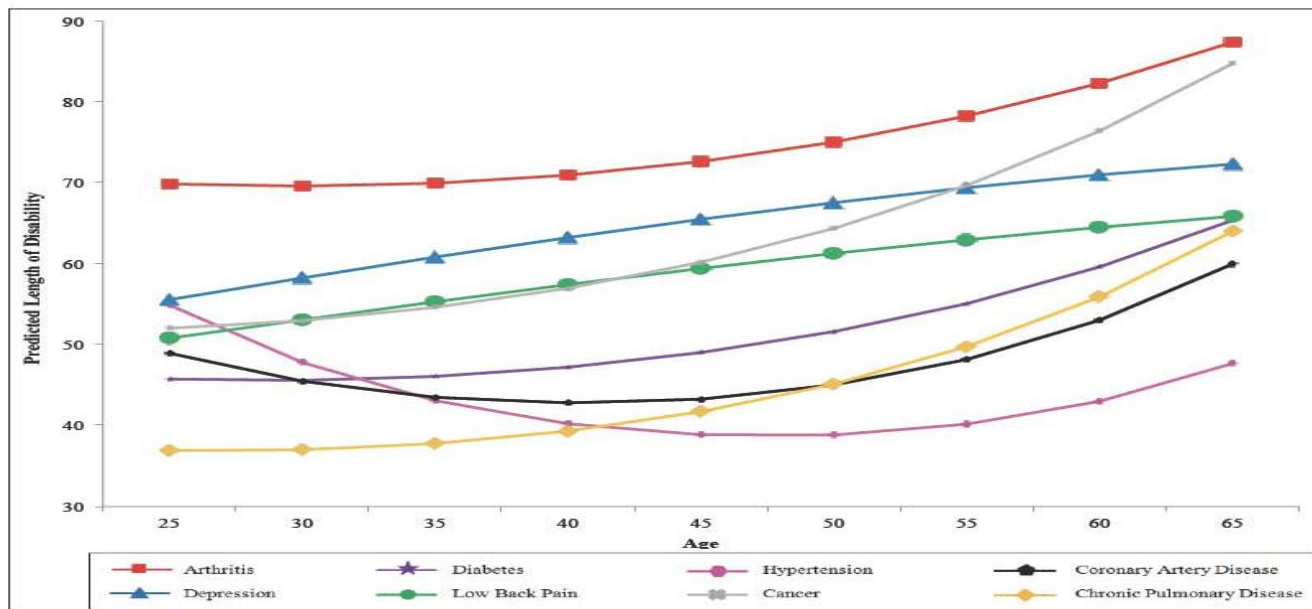
Association between arthritis and productivity loss:

- Job disruptions, absenteeism, presenteeism^{4,5}
- Report being unwell at work¹
- Difficulties with workplace self-management¹

Severity of arthritis-related work disability may increase with age⁶

Arthritis-related sickness absence and age (n = 39,915 US compensation claimants)⁶

Figure 2: Relationship between predicted length of disability and age for chronic health conditions examined in this study



Explaining the association between arthritis and work disability

A number of studies have sought to understand the association between arthritis and work disability.

- **Health:** Disease activity, symptoms severity (e.g., pain, fatigue, activity limitations), disease flares, activity limitations.^{7,8,9}
- **Work:** Supervisor/co-worker support, availability of accommodations, physical and psychological job demands, job tenure.^{10,11,12}
- **Social roles:** Extent to which a person participates in roles outside of work; importance a person places on those roles.¹³

Studies have mainly focused on older samples¹⁴

IS THE EXPERIENCE OF WORKING WITH ARTHRITIS SIMILAR OR DIFFERENT ACROSS THE LIFE COURSE?

Priya



22 years of age

Juvenile arthritis

Diagnosed at 4 years of age;
disease under control

Early childhood educator

- 20 hours/week
- 4 months

Lives with her parents

Nancy



40 years of age

Rheumatoid arthritis

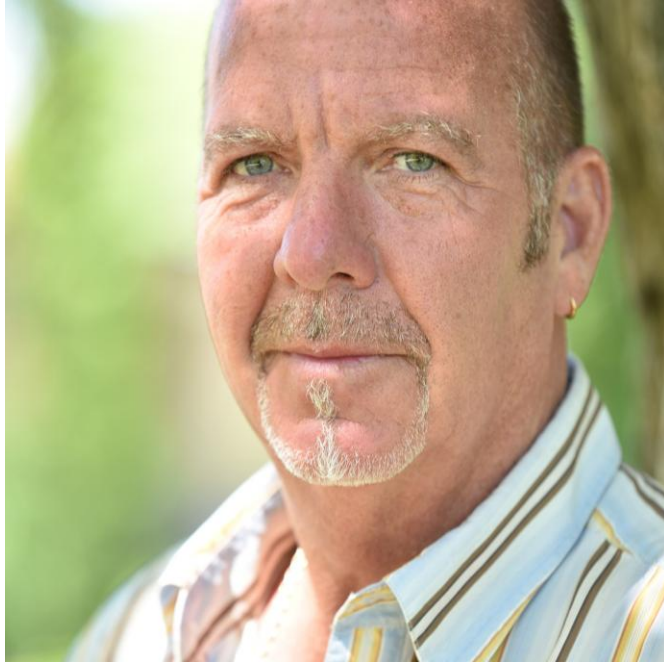
Diagnosed last year; active disease

Marketing executive

- Full-time
- 15 years

One child and married for >10 years

Lorenzo



63 years old

Osteoarthritis

Diagnosed at 55 years; constant moderate pain and fatigue

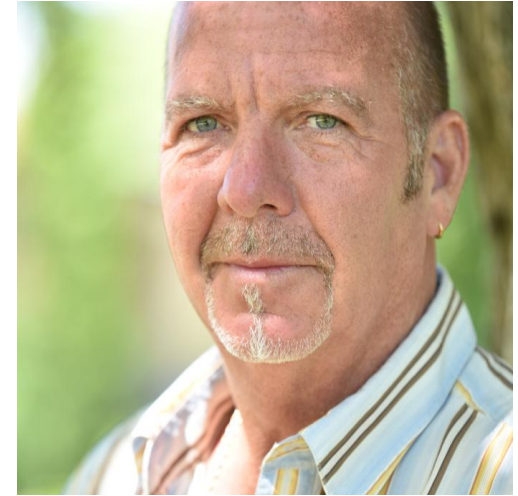
School principal

- Full-time
- 40 years

Married for 40 years

3 children; 9 grandchildren, elderly mother

IS THE EXPERIENCE OF WORKING WITH ARTHRITIS SIMILAR OR DIFFERENT AT VARIOUS PHASES OF LIFE?



Objectives

- 1) Describe the experience of living and working with arthritis at young (18 to 34 years), middle-aged (35 to 54 years) and older adult (55+) life phases.
- 2) Identify key experiences, transitions, or sensitive periods that may shape employment participation at different points in life.
- 3) Examine whether differences or similarities exist in terms of the types of job accommodations, modifications, or workplace supports that are required at different phases of life.

Life course perspective

Sequence of socially defined events and/or roles that an individual enacts over time and how they impact involvement in work.

Life course theory¹⁵

Theoretical orientation that considers a person's time of life and context in shaping involvement in social roles and perceptions regarding involvement in those roles.

Transitions: discrete changes or milestones

Trajectories: sequences of linked social states over a longer-term

Temporality examined in several ways:

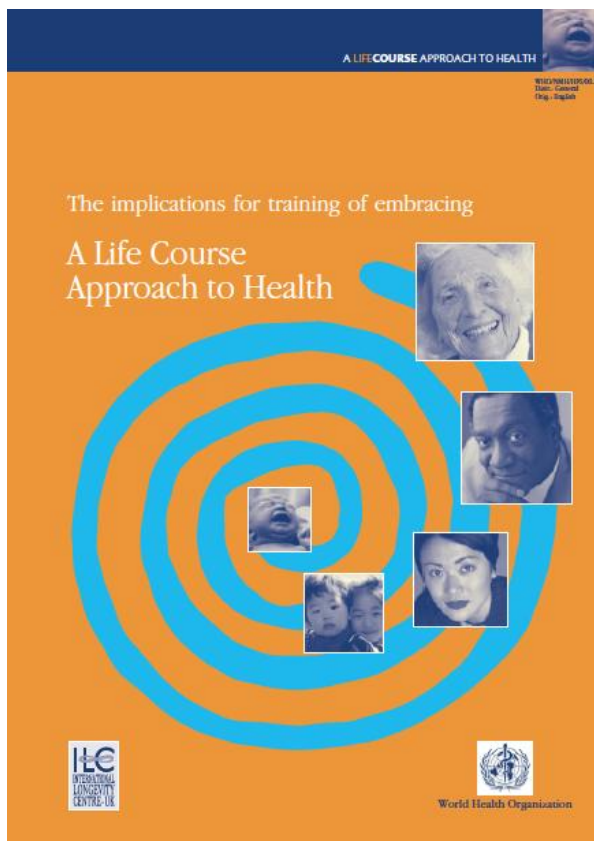
- **Biopsychosocial changes** (life span)
- **Chronological ordering of life events** (timing)
- Personal behaviors and decisions (agency)
- Social network
- Sociohistorical position (time and place)

Application of life course perspective to labour market involvement and health¹⁶

Sensitive periods: *exposure* has a stronger effect on the development of a subsequent outcome than it would at other times

MODEL 4





“The importance of the life course as a framework is often downplayed as ‘common sense’ and its promotion ‘needless’. In reality however, acceptance of this principle has enormous implications on the way an individual’s health is considered, for the training of health care professionals and for the way health systems are developed to cater for individuals’ health care needs.”

**World Health Organization and
International Longevity Centre UK**

METHODS

Methods

Semi-structured focus groups/interviews with young, middle-aged and older adults living with arthritis.

Recruitment was primarily conducted private research services organization and community recruitment.

Eligibility:

- Self-reported physician diagnosis of IA or OA
- Currently employed or employed in the past year

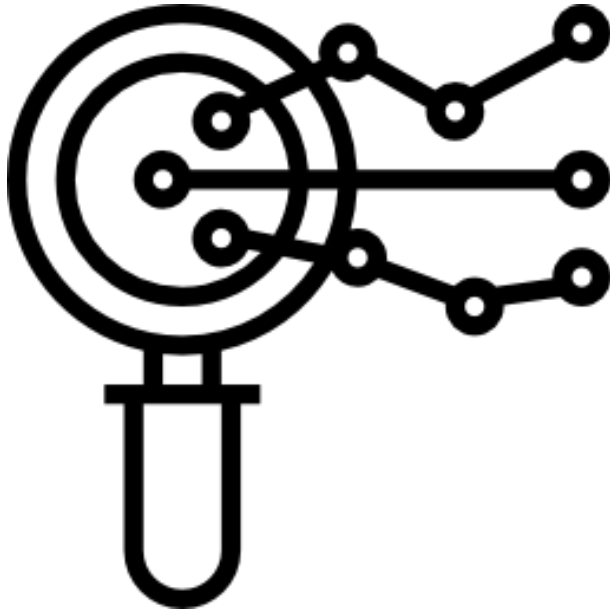
Conducted key informant interviews with community partners to inform all aspects of study design.

Interviews/focus group content



- Experiences of working with arthritis.
- Age shaped their experiences in employment and life roles.
- Probed on the experience of living with arthritis, aging, or career development.
- Special attention was paid to changes to career, health, or social role involvement.

Analytic strategy



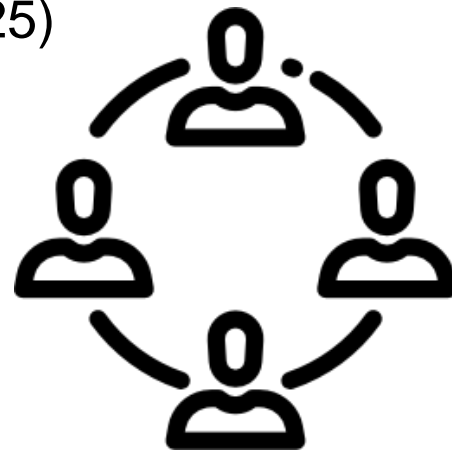
- Transcripts were reviewed for accuracy.
- Developed and revised an initial codebook.
- Primary and secondary coder performed line-by-line coding of transcripts.
- We inductively examined themes that emerged from the data.
- Themes were discussed in analysis meetings where inconsistencies were resolved.

RESULTS

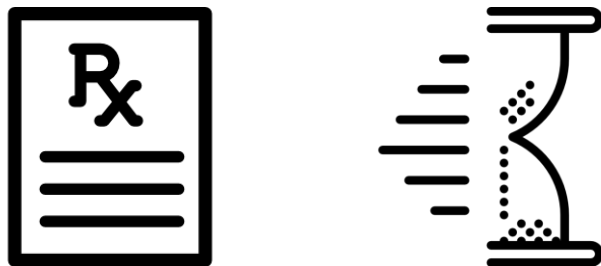
Sample description

Young (n = 7), middle-aged (n = 13) older adults (n = 25)

- 53% female
- 58 % married/living as if married
- 53% osteoarthritis; 47% inflammatory arthritis
- Disease duration shortest for middle-aged adults (11.4 years), when compared to young (18.6 years) and older adults (14.1 years).



Focus group/Interview findings



Young, middle-aged, and older adults discussed that their work experiences were shaped by their arthritis and the transitional experiences that characterized their life phase.

Young adults

Experiences centered on leaving educational roles, and transitioning to work.

Arthritis meant that establishing a career required a great deal of time and energy.



“Being a younger person, it’s forced me to be more focused in my career than most of my friends would, which in some ways... has been a blessing in disguise.... So that’s been oddly useful.” **Aaron, young adult, interview**

Young adults

Expressed a fear of future health-related changes and what that might mean for subsequent employment.



“...instead of it [arthritis] specifically limiting me now I sort of feel like I kind of have an expiration date. Like I’m tired and sore and stiff when I come home and I kind of feel like there’s only so long I can do this [work].” **Anita, young adult, interview**

Young adults

Time and energy re-directed to employment also meant that they had to sacrifice involvement in other important roles and pre-vocational experiences.



*“It felt that I had to get used to resigning my life and my dreams to my condition... I could see my friends being able to do a gap year, go off and do other things with their lives and just try things out and try internships and I didn’t have that luxury. I needed to just work and make sure my job was steady.” **Aaron, young adult, Interview***

Middle-aged adults

Transitioning from relatively good health to living with a disabling condition at a time when they had multiple responsibilities.



“In the early stages it was horrible, it was awful. And pre-diagnosis, I had no idea what was going on. It was probably just one of the worst times of my life. It was just really bad. And having to deal with the sleep deprivation of being a new mother combined with the immobility and then the helplessness...”

Winnie, middle-aged adult, interview

Middle-aged adults

Greater job tenure was protective; credibility built within their places of employment.



“I’m concerned about [how arthritis] impacts my family. Because my job can accommodate me, even if I progress and get worse, they will accommodate me the best they can. But it’s my family I’m worried about. I’m in my early 40’s and it’s really, I don’t know. It wasn’t something I was expecting...” **Geoff, middle-aged, interview**

Older adults

Experiences centered on the work-to-retirement transition.

Prolonged process where a person considers multiple factors in the decision to retire.



“...As you get older, I think you have to realize that you can sort of look at where you want to be and you can plan. I think then you just take it one year at a time, I think that’s the way. I mean I kind of looked at it [that way] the last several years. I would go and then I would re-evaluate at the end of every year and I’d say, ‘okay I feel okay, so I’m going to keep working’.” **Peter, older adult, focus group**

Older adults

Believed they could make valuable contributions to their place of employment.

Balanced job experience with physical ability when planning adaptations.



“So over the years you start saying, 'okay I can't do this or, if I do this, I can't do that,' and slowly you develop a routine, you have to change what your routine, what your interests are to accommodate that because if you continue doing what you were doing you're just going to really hurt yourself ...” **Peter, older adult, focus group**

Older adults

Participants reported feeling worn down and less able to perform work tasks.

Related to both arthritis and age; created ambiguity.



“At 62, you expect things to start to hurt, because you’ve been doing something [at work] all your life... They don’t get better, they get worse, so you have to just deal with that. So it’s hard to know, because I’ve always tried to stay in good shape it’s hard to know whether it’s the aging process or if this is the disease.”
Mark, older adult, focus group

Young/middle-aged vs. older adults

Young/middle-aged indicated that arthritis occurred at a non-normative time that didn't fit into personal and social expectations.

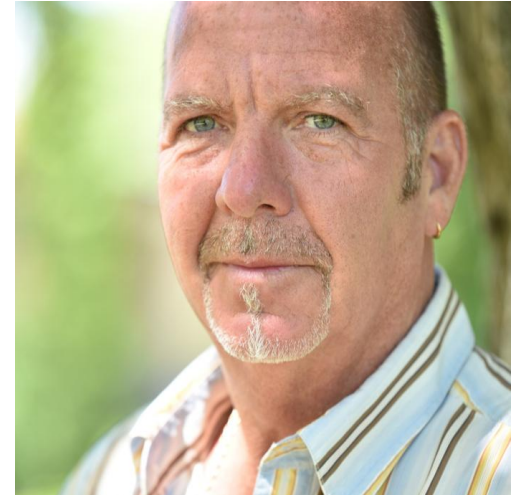
Older adults indicated that an arthritis diagnosis was part of aging.



“I’ve experienced in the past older people being dismissive of it [at work]. Like ‘oh you’re too young for arthritis.’ And that one drives me nuts because I’m in decent shape now but my experiences in the past when it was really bad.... They’ll even grab my hands and ‘oh look at your hands, no you’re fine’.” **Winnie, middle-aged adult, interview**

STUDY IMPLICATIONS

What are the implications of our study findings for Priya, Nancy and Lorenzo?

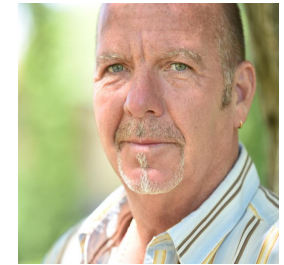


Across the life course participants with arthritis want to work

Employment is an important role; regardless of the life phase there is a desire to actively participate in the labour market.

Effort goes into finding and sustain paid work.

The experience of working with arthritis is *not* uniform across the life course.

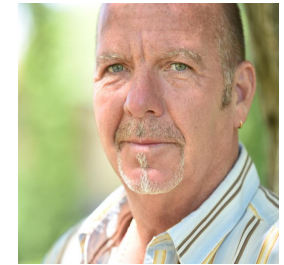


Perceptions of workers with arthritis differ across the life course

Differences in personal and societal views regarding young, middle-aged and older adults with arthritis.

Implications for disclosure and access to accommodations for young and middle-aged adults.

Need to dispel misconceptions regarding arthritis as a disease of the elderly.



Young adults

Highly motivated employees that seek a long-term relationship with employers.



Sacrifice other pre-vocational experiences or social roles to find full-time paid work.

Future research questions:

- What are the implications for career development?
- Are young people at a long-term disadvantage?

Middle-aged adults

Felt secure with their employment participation;
confident in their ability to stay at work.

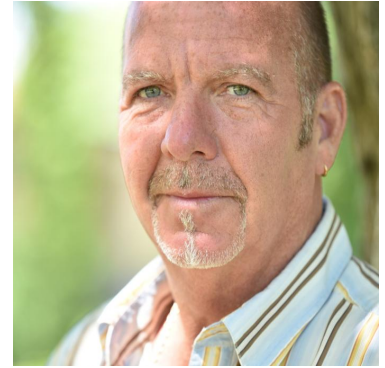
Interventions which promote support may be
important to managing role balance issues.

May only access workplace accommodations
during a crisis.¹⁷

Promote early access to workplace policies,
programs that prevent work disability.



Older adults



Intend on staying employed in their later years.

Benefit from employment which capitalizes on expertise and is also less physically demanding.

Weigh multiple factors in their decision to retire, of which health is only one; Need to go beyond clinical interventions to encourage labour market involvement.

Research is required to understand the work-to-retirement transition to uncover ways to extend working lives.

Future research directions



- Delve deeper into the transitions that are important to young, middle-aged, and older adults.
- Longitudinal studies to examine how key transitions shape subsequent employment.
- Enhance the measurement of age in quantitative studies to include personal and social perceptions of age.
- More insights from younger adults with arthritis, an understudied population.
- Include participants with prolonged difficulties finding work or extended work disability.

Acknowledgement: study team

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Julie Bowring, IWH

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Dr. Monique Gignac, IWH

Consumer

Laurie Proulx, Canadian Arthritis Patient Alliance

Qualitative feedback

Dr. Agnieszka Kosny, IWH

Acknowledgements: community partners



Sam Sullivan

DISABILITY FOUNDATION



Ontario Neurotrauma Foundation

Fondation ontarienne de neurotraumatologie



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Canadian Disability Policy Alliance

Alliance Canadienne concernant
les politiques reliées au handicap



Canadian Wheelchair
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Rick Hansen Institute
Institut Rick Hansen



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Peter Harrison Centre for Disability Sport



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Acknowledgements: academic partners



Funding

This work was supported by a Partnership Grant from the Social Sciences and Humanities Research Council of Canada (grant # 895-2013-1021) for the Canadian Disability Participation Project (www.cdpp.ca)



Social Sciences and Humanities
Research Council of Canada

Conseil de recherches en
sciences humaines du Canada

Canada

Disclosures

The Institute for Work & Health operates with the support of the Province of Ontario. The views expressed in this document are those of the authors and do not necessarily reflect those of the Province of Ontario

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