

# Widespread pain and depression are key modifiable risk factors associated with reduced social participation in older adults

## A prospective cohort study in primary care

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### Abstract

In older adults, reduced social participation increases the risk of poor health-related quality of life, increased levels of inflammatory markers and cardiovascular disease, and increased mortality. Older adults frequently present to primary care, which offers the potential to deliver interventions at the point of care to increase social participation. The aim of this prospective study was to identify the key modifiable exposures that were associated with reduced social participation in a primary care population of older adults.

The study was a population-based prospective cohort study. Participants (n=1991) were those aged ≥65 years who had completed questionnaires at baseline, and 3 and 6-year follow-ups. Generalized linear mixed modeling framework was used to test for associations between exposures and decreasing social participation over 6 years.

At baseline, 44% of participants reported reduced social participation, increasing to 49% and 55% at 3 and 6-year follow-up. Widespread pain and depression had the strongest independent association with reduced social participation over the 6-year follow-up period. The prevalence of reduced social participation for those with widespread pain was 106% (adjusted incidence rate ratio 2.06, 95% confidence interval 1.72, 2.46), higher than for those with no pain. Those with depression had an increased prevalence of 82% (adjusted incidence rate ratio 1.82, 95% confidence interval 1.62, 2.06). These associations persisted in multivariate analysis.

Population ageing will be accompanied by increasing numbers of older adults with pain and depression. Future trials should assess whether screening for widespread pain and depression, and targeting appropriate treatment in primary care, increase social participation in older people.

**Abbreviations:** 95% CI = 95% confidence interval, ACR = American College of Rheumatology, AIC = Akaike Information Criteria, BIC = Bayesian Information Criteria, BMI = body mass index, exp = exponential, GLLMM = Generalized Linear Latent and Mixed Models, GLMM = generalized linear mixed modeling, HADS = Hospital Anxiety and Depression Scale, IRR = incidence rate ratio, KAP = Keele Assessment of Participation, MICE = Multivariate Imputation Chained Equations, n = number, SF-12 = Medical Outcomes Study Short-Form 12.

**Keywords:** cohort, community dwelling, depression, older adults, pain, primary care, social participation

## 1. Introduction

In older adults, reduced social participation increases the risk of poor health-related quality of life, increased levels of

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inflammatory markers and cardiovascular disease, and increased mortality.<sup>[1–5]</sup> Sixty per cent of adults aged 65 years and over experience reduced social participation, increasing to 80% in those aged 85 years and over.<sup>[6]</sup> With population ageing, the number of older adults experiencing reduced social participation will increase.

Developing and delivering interventions to increase social participation has been problematic because the key modifiable risk factors associated with reduced social participation have yet to be identified. Older adults frequently present to primary care and this offers the potential to deliver interventions at the point of care to increase social participation.<sup>[7]</sup> Physicians could assess and target modifiable exposures to increase social participation. These modifiable exposures should ideally be relatively easy to screen for and easy to change.<sup>[8]</sup>

The aim of this prospective study was to identify the key modifiable exposures of reduced social participation in a primary care population of older adults. The study specifically sought to determine the relative contribution of exposures that were common in older people, that theoretically reduced social participation, could be easily assessed and identified at the point of care (i.e., during consultation to primary care), and are amenable to change.<sup>[9–11]</sup>

## 2. Methods

### 2.1. Design overview, setting, and participants

In the United Kingdom, 98% of the population are registered with a general practice, and these registers provide convenient sampling frames of the local general population and allow survey data to be linked to medical record data.<sup>[12]</sup> This study draws on a well-established population-based cohort (the North Staffordshire Osteoarthritis Project [NorStOP]) of older people.<sup>[13]</sup> A total of 4670 individuals aged  $\geq 65$  years, registered with 6 general practices in North Staffordshire, United Kingdom, formed the cohort to be followed up 3 (2005) and 6 years (2008) later. The North Staffordshire Local Research Ethics Committee granted approval, and all participants gave written consent to participate.<sup>[13]</sup>

### 2.2. Measuring social participation

Social participation was measured using the Keele Assessment of Participation (KAP)<sup>[14]</sup> at baseline, 3, and 6-year follow-up. This short self-complete instrument was designed to measure social participation from the perspective of the individual in 11 aspects of life (e.g., looking after dependents, attending social activities). Items are phrased to capture performance (“I have”), individual judgment, and the nature and timeliness of participation (“as and when I have wanted”).<sup>[14]</sup> Responses are on a 5-point ordinal scale (all/most/some/a little/none of the time). The reliability and validity of individual KAP items have been established as adequate for providing estimates of reduced social participation in population studies.<sup>[14,15]</sup> Participants were classified as experiencing reduced participation in an aspect of life if they did not participate in it “as and when I wanted” for “all” or “most of the time”.<sup>[14]</sup> The resulting 11 binary items were then summed to give a total score ranging from 0 to 11.<sup>[14]</sup> Higher KAP scores indicate increasing reduction in social participation. KAP scores were calculated at all 3 time points.

### 2.3. Exposures of reduced social participation

The exposures included in this study are common in older people, theoretically reduce social participation, and could be easily assessed and identified at the point of contact (i.e., during consultation to primary care and are amenable to change).<sup>[9–11]</sup> These were musculoskeletal pain, multimorbidity, anxiety, depression, cognitive impairment, body mass index (BMI), demographic (age, sex) and socioeconomic factors, and physical function, and were measured at all 3 time points.

**2.3.1. Musculoskeletal pain.** Participants were asked “During the last month have you had an ache or pain which has lasted for 1 day or longer?” Those subjects who answered positively were asked to indicate on a 2-view (front and back) blank body manikin the location of their pain. At each time point, participants’ reports of pain were categorized into one of 3 pain groups: “widespread pain,” “some pain,” or “no pain.” Widespread pain was classified according to the American College of Rheumatology (ACR) criteria used in their definition for fibromyalgia,<sup>[16]</sup> which require pain to be present in the left and right hand sides of the body, above and below the waist, and in the axial skeleton. The “some pain” group were those participants who reported pain that did not satisfy the ACR criteria for widespread pain. These methods to determine the location and extent of pain are commonly used

in population-based studies of pain, and have been shown to be valid and reliable.<sup>[17,18]</sup>

**2.3.2. Multimorbidity.** A count of morbidities was generated from participants’ general practice records. During consultations, general practitioners used the Read system to code all morbidity.<sup>[19]</sup> Morbidity data (i.e., symptoms and diseases) in this system are grouped under 18 main chapters (Appendix 1). Consultation for at least 1 morbidity in each of the 18 chapters was collected for 3 time periods; 18 months before baseline, between baseline and 3-year follow-up, and between 3 and 6-year follow-up. Participants with at least 4 (of 18) recorded morbidities within each time period were classified as “multimorbid.”<sup>[20]</sup>

**2.3.3. Anxiety and depression.** The Hospital Anxiety and Depression Scale (HADS) assessed anxiety and depression.<sup>[21]</sup> HADS consists of 14 items each scored on a Likert scale of 0 to 3: 7 items ask about symptoms of anxiety and give a total score of 0 to 21, and 7 items ask about symptoms of depression and give a total score of 0 to 21. Based on their scores separately for anxiety and depression, participants were classified as noncases (score 0–7), possible cases (8–10), and probable cases (11–21).<sup>[21]</sup>

**2.3.4. Cognitive impairment.** Participants completed the Cognitive and Alertness Behaviour Subscale of the Functional Limitations Profile.<sup>[22]</sup> This scale has 10 items that ask about alertness and ability to concentrate. Items are scored as 0 (no cognitive complaint) or 1 (cognitive complaint), with raw scores categorized to indicate “no cognitive complaint” (score 0) and “cognitive complaint” (score  $>0$ ).

**2.3.5. BMI.** Calculated from self-reported height and weight (weight [kg]/height [m<sup>2</sup>]) and categorized into standard BMI groups normal weight (BMI 20–24.9 kg/m<sup>2</sup>), underweight (BMI  $<20$  kg/m<sup>2</sup>), overweight (BMI 25–29.9 kg/m<sup>2</sup>), and obese (BMI  $\geq 30$  kg/m<sup>2</sup>).<sup>[23]</sup>

**2.3.6. Physical function.** The physical function is measured using the physical functioning scale of the Medical Outcomes Study Short Form-36. Ten items measured the limitation in the individual’s capacity to complete basic tasks such as lifting and walking; scores range from 0 to 100, and higher scores indicate better function.<sup>[24]</sup>

**2.3.7. Socioeconomic characteristics.** Current occupational class (nonmanual, manual)<sup>[25]</sup> and educational attainment (finished education on leaving school; gone onto full-time education including college or university) were assessed.

### 2.4. Statistical analysis

Analysis was performed in subjects who had complete outcome data at all 3 time points. The baseline characteristics were described overall and stratified by baseline social participation status (no restrictions, one or more restrictions). Between-group differences for age and physical function were tested by a Kruskal–Wallis test, and for all other variables, by a chi-square test. To test for associations between exposures and decreasing social participation over 6 years, a generalized linear mixed modeling (GLMM) framework was used. As restricted social participation data were characterized by excess zeros (at each time point, more than 50% of the sample had a score of 0), a “2-part joint mixed model” was used to model data and provide coefficient estimates (see Appendix 2 for rationale). Coefficient estimates produced by the 2-part joint mixed model were

transformed and expressed as incidence rate ratios (IRRs) with 95% confidence intervals (CI) and are interpreted in the same way as in a Poisson mixed model (e.g.,  $\exp(0.62) = \text{IRR } 1.86 =$  increased event prevalence of 86% for a particular characteristic to its reference).<sup>[26]</sup>

Initially, univariate models were constructed to examine the association between exposures and reduced social participation across the 3 time points, adjusting for age and sex. A multivariate model was then constructed that included all exposures except physical function, because it has previously been found to mediate the impact of health conditions on restricted social participation. Physical function was then included in a final multivariate model. Except for sex, occupational class, and educational attainment, all covariates were modeled as time-dependent. The use of a mathematical function to model the development of the KAP score over time always assumes a particular shape such as linear or quadratic term. Time was included in the multivariate model as a categorical variable using appropriate dummy variables and has the added advantage of not having to assume a certain shape of development.

Model goodness of fit was assessed by Akaike Information Criteria (AIC) and Bayesian Information Criteria (BIC), with lower values indicating improved model fit. All analyses were performed using Stata (v 12)<sup>[27]</sup> Generalized Linear Latent and Mixed Model (GLLAMM) program with adaptive quadrature<sup>[28]</sup> was used to implement the models.

Sensitivity to participant attrition and missing data was examined by imputing data using Multivariate Imputation Chained Equations (MICEs) using the “countimp” command in R; 100 imputations were used.<sup>[29]</sup> There were no differences in the strength or significance of associations when the analysis was conducted on the imputed data and compared with the complete case analysis. In this study, we have presented the results from the complete case analysis.

### 3. Results

#### 3.1. Participant flow

At 3 years, of the 4670 eligible subjects, 436 (9.3%) had died and 505 (10.8%) were no longer at their mailing address (Fig. 1). Of the remaining 3729 subjects, 3066 (82.4%) responded. At 6 years, a further 244 (8.0%) had died, 143 (4.7%) had moved address, leaving 2679 (71.8%) eligible participants. Of those, 1991 (74.3%) responded. Compared with those subjects who had moved address or withdrew from the study ( $n=1999$ ), those who were included in the analysis were younger (mean age 71.4 vs 74.3 years;  $P < 0.001$ ), were more likely to be men (52.1% vs 48.2%), had higher mental and physical health-related quality-of-life scores (mean SF-12 mental component score: 51.6 vs 48.8;  $P < 0.001$ ; mean SF-12 physical component score: 40.7 vs 37.3;  $P < 0.001$ ), had higher levels of participation (no restriction: 55.9% vs 38.6%;  $P < 0.001$ ), and were less likely to be depressed (possible/probable cases of depression: 15.9% vs 26.6%;  $P < 0.001$ ) or anxious (34.7% vs 39.6%;  $P < 0.001$ ). There was no difference in pain prevalence (some pain: 46.6% vs 46.9%;  $P = 0.97$ ) or education level (gone on to further education: 8.0% vs 9.7%;  $P = 0.06$ ).

#### 3.2. Subject characteristics

Of the 1991 participants, mean age was 71.4 (standard deviation [SD] 5.3) years, 54% were women, and 88% had finished education on leaving school (Table 1). At baseline, 44% had a KAP score of  $\geq 1$  restrictions in social participation; this increased to 49% at 3 years and 55% at 6 years. The prevalence of 1 or more restrictions at baseline was higher in participants who were female, had finished education on leaving school, were in manual occupational class, were outside the normal range of BMI, were classified as having a possible or probable case of anxiety or depression, and had cognitive impairment and multimorbidity (Table 1).

#### 3.3. Predictors of restricted social participation

The results from the 2-part joint mixed models are presented in Table 2. After adjusting for age and sex, all exposure variables were associated with increased restriction in social participation. Across the 6 years, the strongest association in the univariate analysis was with widespread pain; the prevalence of increased restriction in those with widespread pain was 167% (IRR 2.67, 95% CI 1.91, 3.73) compared with those with no pain. In a multivariate model (Table 2, model 2), some pain (IRR 1.69, 95% CI 1.43, 1.99), widespread pain (IRR 2.06, 95% CI 1.72, 2.46), anxiety (possible: IRR 1.32, 95% CI 1.20, 1.44; and probable: IRR 1.36, 95% CI 1.22, 1.53), depression (possible: IRR 1.62, 95% CI 1.46, 1.79); and probable: IRR 1.82, 95% CI 1.62, 2.06), cognitive impairment (IRR 1.46, 95% CI 1.33, 1.61), multimorbidity (IRR 1.23, 95% CI 1.13, 1.33), and manual occupation (IRR 1.23, 95% CI 1.11, 1.36) were independently associated with increased restriction in social participation across the 6 years. Finally (Table 2, model 3), physical function was added and was found to be protective against restricted social participation (IRR 0.98, 95% CI 0.98, 0.99).

### 4. Discussion

In a large primary care population of older adults, this study has identified widespread pain and depression as the key modifiable

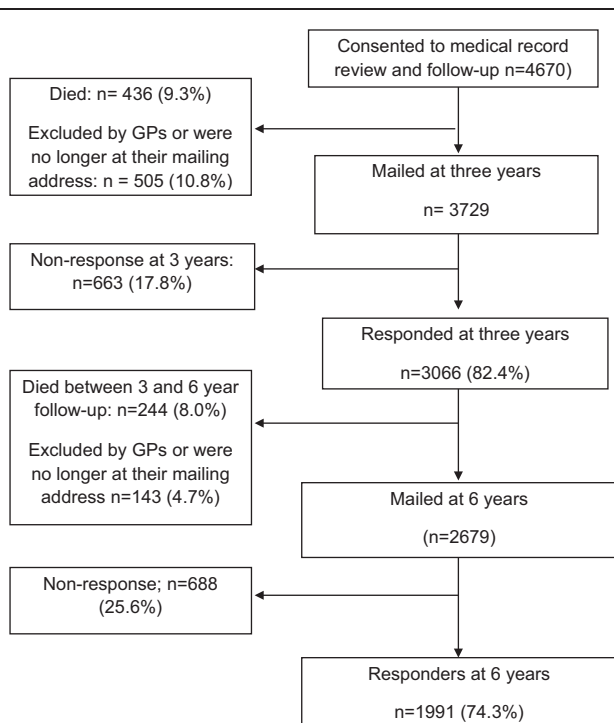


Figure 1. Flow of study participants.

**Table 1****Participant characteristics at baseline for all subjects and stratified by participation restriction at baseline (N = 1991).**

		All participants (N = 1991)	Stratified by KAP score		P
			0 (n = 1112)	≥1 (n = 879)	
Sex	Male	910 (46)	549 (49)	361 (41)	<0.001
	Female	1081 (54)	563 (51)	518 (59)	
Age, years*		71.4 (5.3)	71.1 (5.0)	71.9 (5.6)	<0.001
Further education†	Yes	188 (10)	124 (11)	64 (8)	0.004
	No	1750 (88)	964 (89)	786 (92)	
Occupational class‡	Nonmanual	1006 (54)	628 (59)	378 (47)	<0.001
	Manual	861 (46)	431 (41)	430 (53)	
Pain	None	493 (27)	354 (35)	139 (18)	<0.001
	Some	865 (48)	473 (46)	392 (50)	
	Widespread	450 (25)	191 (19)	259 (33)	
BMI§	Normal (20–24.9)	711 (36)	426 (38)	285 (32)	0.005
	Underweight (<20)	52 (3)	26 (2)	26 (3)	
	Overweight (25–29.9)	852 (43)	479 (43)	373 (42)	
	Obese (≥30)	297 (15)	145 (13)	152 (17)	
Physical function*		40.7 (11.9)	48.4 (9.7)	40.2 (11.1)	<0.001
Cognitive impairment	No	1069 (54)	712 (64)	357 (41)	<0.001
	Yes	922 (46)	400 (36)	522 (59)	
Multimorbidity¶	Low comorbidity (0–3)	1193 (64)	726 (70)	467 (56)	<0.001
	Multimorbidity (4+)	672 (36)	306 (30)	366 (44)	
Anxiety	No	1300 (65)	824 (74)	476 (54)	<0.001
	Possible/probable	691 (35)	288 (26)	403 (46)	
Depression	No	1675 (84)	1031 (93)	644 (73)	<0.001
	Possible/probable	316 (16)	81 (7)	235 (27)	

BMI = body mass index, KAP = Keele Assessment of Participation.

All values are n (%) except \* which are median (standard deviation).

† Education information was missing for 53 patients.

‡ Occupational class was missing for 124 patients.

§ BMI was missing for 79 patients.

¶ Multimorbidity information was missing for 126 patients.

factors associated with reduced social participation. The presence of both of these conditions in potential primary care consulters is common; in this study, 1 in 4 adults at baseline had widespread pain. Worldwide changing demographics mean that there will be increasing numbers of older adults with pain and depression. These are identifiable in primary care and can be targeted to increase social participation and prevent subsequent health problems. Case-finding questions for depression are validated<sup>[30,31]</sup> and could be used by the family physician to detect depression, and manage appropriately.<sup>[32]</sup> There are barriers, however, to the identification of depression in older people and those with multimorbidities.<sup>[33,34]</sup> There are evidence-based interventions, both pharmacological and nonpharmacological, for managing depression in primary care, which could be delivered by the family physician or delivered by professionals in the wider primary care team.<sup>[35]</sup> In addition, sign-posting older people with depression to third-sector services may reduce mental health symptoms and increase social participation.<sup>[36]</sup>

Assessing pain and its impact, and offering appropriate analgesia and advice about activity, including referral to local activity groups, are simple interventions that could be delivered in primary care. However, if pain persists, our results suggest that targeting physical function may maintain social participation. In additional analysis, the extent of mediation of physical function on the effect of musculoskeletal pain on restricted social participation was calculated using the product of the coefficients method; physical function explained 48.9% of the effect of pain status on restricted social participation. Physiotherapy, exercise

classes, and psychological interventions that address the barriers to physical function are example treatments that may improve physical functioning despite the presence of pain.<sup>[37]</sup> Future research should focus on case-finding for pain and depression in older adults in primary care and examine if it maintains social participation and subsequently prevents physical and mental health problems.<sup>[38]</sup>

This study has a number of strengths. It was a large population-based study of older community-dwelling individuals. Data were collected prospectively and were allowed the contemporaneous relationship between exposures and participation restriction to be determined across a 6-year period. Although some of the exposures (e.g., depression) may be a consequence of reduced social participation, in additional sensitivity analysis using regression modeling, the patterns of association between baseline exposures and the onset of reduced social participation at 3 years (i.e., moving from no restriction at baseline to 1 or more at 3-year follow-up) were similar to those presented using the 2-part joint mixed model. The KAP is the first instrument to be developed and used to measure social participation restriction in population studies.<sup>[39]</sup> The statistical approach (i.e., use of 2-part joint mixed model) to modeling produced subject-specific coefficients which are considered to be more accurate estimates of the underlying mechanisms than simpler approaches that do not acknowledge that the equi-dispersion assumption is not met, which may result in biased estimates and misleading conclusions.<sup>[26]</sup>

Study limitations were as follows: social participation was measured by self-report. Although this is susceptible to



**Table 2**

**Risk factors of increasing participation restriction.**

Variables		Model 1* IRR (95% CI) <sup>§</sup>	Model 2 <sup>†</sup> IRR (95% CI)	Model 3 <sup>‡</sup> IRR (95% CI)
Pain	None	1	1	1
	Regional	1.81 (1.55, 2.12)	1.69 (1.43, 1.99)	1.37 (1.17, 1.60)
	Widespread	2.67 (1.91, 3.73)	2.06 (1.72, 2.46)	1.45 (1.23, 1.72)
Sex	Male	1	1	1
	Female	1.42 (1.28, 1.58)	1.16 (1.05, 1.29)	1.04 (0.95, 1.14)
Age, years	60–69	1	1	1
	70+	1.29 (1.16, 1.46)	1.22 (1.11, 1.34)	1.04 (0.95, 1.13)
Further education	Yes	1	1	1
	No	1.27 (1.03, 1.57)	1.12 (0.92, 1.36)	1.06 (0.90, 1.25)
Occupational class	Nonmanual	1	1	1
	Manual	1.53 (1.37, 1.71)	1.23 (1.11, 1.36)	1.17 (1.07, 1.29)
BMI	Normal	1	1	1
	Underweight	1.25 (1.06, 1.48)	1.16 (0.98, 1.38)	1.07 (0.90, 1.27)
	Overweight	1.00 (0.92, 1.10)	1.06 (0.96, 1.16)	1.01 (0.93, 1.09)
	Obese	1.26 (1.12, 1.42)	1.15 (1.03, 1.30)	0.95 (0.85, 1.06)
Cognitive impairment	No	1	1	1
	Yes	1.75 (1.60, 1.92)	1.46 (1.33, 1.61)	1.32 (1.21, 1.44)
Multimorbidity	Low comorbidity	1	1	1
	High comorbidity	1.31 (1.21, 1.42)	1.23 (1.13, 1.33)	1.12 (1.04, 1.21)
Anxiety	No	1	1	1
	Possibly	1.62 (1.49, 1.77)	1.32 (1.20, 1.44)	1.23 (1.13, 1.35)
	Probably	1.92 (1.75, 2.12)	1.36 (1.22, 1.53)	1.28 (1.15, 1.42)
Depression	No	1	1	1
	Possibly	1.86 (1.70, 2.05)	1.62 (1.46, 1.79)	1.31 (1.18, 1.44)
	Probably	2.18 (1.95, 2.41)	1.82 (1.62, 2.06)	1.42 (1.26, 1.60)
Physical function	—	—	—	0.98 (0.98, 0.99)
	$\sigma_1^2$ (SE) <sup>¶</sup>	1.249 (0.132)	0.764 (0.116)	0.552 (0.094)
	$\sigma_2^2$ (SE) <sup>¶</sup>	0.138 (0.076)	0.208 (0.115)	0.036 (0.026)
	$\sigma_3^2$ (SE) <sup>¶</sup>	0.302 (0.124)	0.314 (0.128)	0.134 (0.055)
LR test $\chi^2$ (P value)		34.27 (<0.001)	26.16 (<0.001)	26.04 (<0.001)
AIC		15034.52	11333.32	10573.74
BIC		15074.45	11461.95	10708.18

AIC = Akaike Information Criteria, BIC = Bayesian Information Criteria, BMI = body mass index, CI = confidence interval, IRR = incidence rate ratio, LR test = likelihood ratio test with regards to model excluding random coefficient for pain status, SE = standard error.

\* adjusted for time, age and gender.

<sup>†</sup> adjusted for time, age, gender, socio-economic status and comorbidity (BMI = cognitive impairment, multimorbidity, anxiety, depression).

<sup>‡</sup> adjusted for time, age, gender and socio-economic status (educational attainment and occupational class, comorbidity (BMI = cognitive impairment, multimorbidity, anxiety, depression) and physical capacity.

<sup>§</sup> CI = Confidence Interval, IRR = Incidence Rate Ratio.

<sup>¶</sup>  $\sigma_1^2$  = random intercept variance,  $\sigma_2^2$  ( $\sigma_3^2$ ) = random coefficient for regional (widespread) pain variance.

measurement error, it is the most appropriate method to capture an individual’s performance in social activities.<sup>[39]</sup> The self-report of impairments and functional problems has been shown to be accurate in older adults,<sup>[40]</sup> and validated instruments (e.g., Hospital Anxiety and Depression scale<sup>[21]</sup> and Short Form-36<sup>[24]</sup>) were used to measure anxiety, depression, and physical function. As is common in population-based longitudinal studies, there was attrition and missing data throughout the 6 years. The extent of missing exposure data during the entire 6 years was small, with typically 3% to 6% of patients missing data on BMI, physical function, multimorbidity, education, and/or occupational class. Our analyses comprised of only those subjects who had participation measured at all 3 time points, which resulted in 1999 subjects being excluded as a result of being lost to follow-up. However, reanalyzing the data after imputation of missing data for such participants who were still alive at the end of 6-year follow-up led to similar conclusions to those based on complete data analysis. The generalizability of the study may be limited by the characteristics of the study sample; the area covered by the study is more deprived on health, education, and employment, but with fewer barriers to housing and services, than England as a

whole. The 3-year gap between time points may miss some of the changes in status of predictors and social participation. Finally, there may be other predictors (e.g., social networks) which may be important, but which were not included in this study.

The study identifies that widespread pain and depression are the key modifiable factors associated with reduced social participation. The sheer frequency of widespread pain in older adults means that there will be a large number of primary care consulters at risk of reduced social participation, which puts them more at risk of developing further health problems. Both widespread pain and depression are identifiable in primary care and modifiable. Further studies that screen for widespread pain and/or depression could intervene to potentially increase social participation and prevent further physical and mental health problems in older adults.

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## Appendix 1

During consultations to general practice, general practitioners use the Read system to code all morbidity to eighteen diagnoses codes ([http://www.gp-training.net/it/synergy\\_archive/synergy/readcode.htm](http://www.gp-training.net/it/synergy_archive/synergy/readcode.htm)). These are (A) infectious/parasitic diseases (b) Neoplasms, (c) endocrine/metabolic (D) blood diseases (E) mental disorders, (F) nervous system/senses (G) circulatory system (H) respiratory diseases (J) digestive diseases (K) genito-urinary system (M) skin/subcutaneous tissue (N) musculoskeletal (P) congenital abnormalities (Q) perinatal conditions (R) Ill-defined conditions/working diagnoses (S) Injury/poisoning (T) causes of injury poisoning.

## Appendix 2

Participation data was characterised by excess zeros (at each time point, more than 50% of the sample had a score of 0) and hence application of standard Poisson count model would result in violation of model assumption of equidispersion. The alternative is to employ a two-part model such as zero inflated Poisson model,<sup>[26]</sup> which is an extension of the standard Poisson model, and models simultaneously the odds of an individual having one or more restrictions (Binomial process) and the relative risk of an increase in participation score (Poisson process). This model however produces two sets of coefficient estimates, one for each process, rendering reporting and interpretation of results somewhat cumbersome. An extension is the two-part *joint* model, where the distribution of the dependent variable is split according to Binomial/Poisson distribution, resulting in only one set of coefficient estimates.

To account for repeated measures design of our study, random effects (assumed to be normally distributed with mean zero and fixed variance) are incorporated within the Binomial/Poisson linear predictor component. This two-part *joint mixed* model, which is used in this paper, has been advocated to be a better method of analysing data with excess zeros in terms of model fit compared to linear or Poisson mixed models.<sup>[27]</sup> Initially we model only the random intercept, followed by inclusion of random coefficients for time-dependent covariates; using likelihood ratio tests, significance of variances of random coefficients assigned to time dependent variables was determined. Only the effect of pain status on participation over time varied significantly between individuals, hence random coefficients pertaining to some and widespread pain were the only ones retained in the models. The single coefficients produced by the two-part joint mixed model were transformed and expressed as Incidence Rate Ratios (IRR) with 95% confidence interval (CI) and are interpreted in the same way as a Poisson mixed model (e.g.,  $\exp(0.62) = \text{IRR } 1.86 = \text{increased prevalence of } 1.86$ ).<sup>[27]</sup>

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