# BRINGING MSK CONDITIONS IN FROM THE CARE PLANNING COLD - A FEASIBILITY STUDY

# **FINAL REPORT**

June 2019



# Foreword from Liam O'Toole, CEO, Versus Arthritis

Arthritis and related conditions affect 18.8 million people across the UK. People with these conditions often experience ongoing pain and fatigue making their everyday lives difficult. These conditions steal quality of life from millions of people every day and can lead to a loss of their independence. But there is much that can be done to change this.

Versus Arthritis works alongside volunteers, healthcare professionals, researchers, friends and families to do everything we can to push back against arthritis. Together, we develop breakthrough treatments, campaign for arthritis to be a priority and provide support. Our remit covers all types of musculoskeletal conditions, including rheumatoid arthritis, osteoarthritis, back pain and osteoporosis. Through our work we identify opportunities to improve the services, support and information available to people with musculoskeletal conditions to drive improvement.

We recognised the importance of care planning for people with musculoskeletal conditions in our 'Care Planning and Musculoskeletal Health' in 2014. We found that only 12% of people with a musculoskeletal condition reported having a care plan. The report recommends this approach to meet the needs of people with arthritis and related conditions, proactively supporting and enabling people to live well.

Building on from the report, we funded the Year of Care Partnerships team to develop and test this approach for people with arthritis. Based in the North East of England, they have worked with local GPs, people with arthritis and specialists to implement Care and Support Planning for this group. In this new report, they report on their learning about how to make Care and Support Planning available in primary care for people with arthritis.

This report from Year of Care Partnerships highlights the unmet need of people with musculoskeletal conditions and the prominence that pain has in people's lives. It also provides hope that this person centred approach allows people to express what is important to them as well as being able to better access the information and support they need. This approach was well liked by clinicians and the people who took part, but it does expose a need to build confidence and training amongst those working in primary care.

The authors have also included a series of recommendations for change. One of the report's key areas is ensuring that the management of musculoskeletal conditions are truly embedded in primary care and given a similar prominence as other long-term conditions. The report is timely, given the growing numbers living with multiple long-term conditions and the backdrop of the NHS Long Term Plan emphasising the important role of primary care in personalisation and proactive care. Versus Arthritis is keen to work with decision makers, healthcare practitioners, fellow charities and others with an interest in this important area so that together we can push back against arthritis.

Liam O'Toole, CEO, Versus Arthritis

### **Foreword**

Arthritis is the biggest cause of pain and disability in the UK, affecting around 20% of the general population. In 2014 Arthritis Research UK (ARUK) published a Report 'Care Planning in Musculoskeletal Health' which recommended that care and support planning (CSP) should be made available to people living with musculoskeletal (MSK) conditions either alone or together with other long-term conditions (LTCs). The study we report here 'Bringing MSK conditions in from the care planning cold - a feasibility study' demonstrates how this can be achieved in practice and confirms the benefits.

We describe a two phased approach designed to tease out the issues of practical delivery and develop the tools and MSK specific resources to enable CSP to become a normal part of care for people living either with single MSK conditions or more usually as one of a number of LTCs.

In the first Phase we developed the core tools and resources for practices to use and then demonstrated their transferability to other practices in Phase 2. Throughout we confirmed that CSP has the same positive benefits for those living with MSK as has been reported for other conditions and is rewarding for staff. But there is also much unmet need. CSP enabled issues of pain and problems of daily living to be highlighted and addressed sometimes for the first time and focussed on solutions within the community rather than traditional services and medicines.

The Report also describes why tools alone will not be enough to ensure the benefits of CSP are widely available and makes recommendations. Training in MSK is important for health care professionals (HCPs) who often lack confidence as well as knowledge when discussing symptoms and function, and less biomedically focused approaches to solutions.

Many primary care communities will struggle with the numbers of people with MSK conditions. This study was possible because it involved practices who were already experienced in and resourced to carry out CSP for people living with multiple LTCs. In this study practices were given additional funding to expand CSP to people with MSK conditions alone. Potentially over half of those living with MSK have other conditions. Providing them with a single CSP conversation, however many conditions or issues they live with, provides a more personalised approach as well as being time and resource efficient for the practices. For those with MSK conditions alone, where the study identified a great deal of unmet need that was addressed via CSP, there is currently no policy or resource to provide this. The study timescale did not allow us to investigate the possibility that some people might benefit more than others, and this requires further investigation and longitudinal follow up.

### This Report and appendices:

- 1. Provides links to the Phase 1 Report that preceded it and contains early findings.
- 2. Describes the details of the additional learning in Phase 2.
- **3.** Makes suggestions for Versus Arthritis, policy makers and commissioners about how the benefits demonstrated here might be made available more widely.
- 4. Brings together practical learning in a supplementary document for delivery teams

**Signed:** Core CSP MSK Study Team

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# **Executive summary**

This Final Report brings together the learning from both Phases of a feasibility study of care and support planning (CSP) for people living with joint, muscle and bone (MSK) conditions. It builds on the detail and lessons in the Phase 1 Report, describes additional learning and highlights dilemmas and further questions which warrant future discussion and investigation. It also celebrates the successes of the study and describes some of the benefits seen by individuals who live with MSK conditions.

Those involved found the CSP approach refreshing and focused on supporting them to live well with their MSK conditions, often allowing people to talk about issues that they previously felt they could not raise with a health care professional.

In Phase 1 Year of Care Partnerships™ (YOCP) worked intensively with three general practices serving diverse communities to identify the issues involved in establishing CSP as part of routine care for people living with MSK conditions as outlined in the Arthritis Research UK (ARUK)¹ Document 'Care Planning and Musculoskeletal health'. In Phase 2 three additional practices joined Phase 1 practices to test the transferability of the tools and resources developed. They worked in depth on the implementation issues highlighted in Phase 1 relating to the introduction of CSP for two groups - those living with MSK conditions alone ('MSK only') or in combination with multiple LTCs ('MSK plus').

### High level learning about CSP in MSK conditions

- The core components of CSP (using the YOCP approach) are suitable for people living with the three groups of MSK conditions defined by ARUK (inflammatory conditions, conditions of musculoskeletal pain, osteoporosis and fragility fractures).
- CSP is applicable and feasible for those with either an MSK condition alone ('MSK only') or those who also live with other LTCs ('MSK plus').
- The CSP process, which includes a preparation step, enables previously undisclosed topics related to symptoms, daily living and overall function in MSK conditions to be raised, discussed and recorded, revealing a large amount of remediable unmet need.

"There is absolutely no doubt in my mind that this IS a forgotten/ neglected group" **GP** "I've never talked to anyone about this" **Person with MSK condition** 

 People living with MSK conditions value the opportunity to get prepared for a CSP conversation, and to have an open discussion based on their own agenda, in the same way as people with other LTCs.

"It feels like a new channel of communication has been opened" **Nurse practitioner** "People want to be "heard" they often feel they're neglected when it comes to musculoskeletal conditions" **Evaluator** 

 People reported a wide range of positive benefits, including learning more about their conditions, significant behaviour change, or involvement in new activities which is some cases were life changing.

"Totally thrilled, I have been out of the house by myself for the first time in years" **Person** with MSK condition

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<sup>&</sup>lt;sup>1</sup> Now Versus Arthritis

- Pain was a consistent major theme for people with MSK conditions and required a more systematic, holistic and skilful approach (to prevention and management within consultations), linked with better community support.
- CSP enables a shared discussion about medicines. Prescription drugs for pain, including opioids
  were often stopped or reduced and replaced by over the counter (OTC) medicines and
  alternative approaches. Some people with gout and fragility syndromes received appropriate
  drugs for the first time.
- CSP acts as the pivot which moves the focus of ongoing support towards activities in the community rather than relying solely on medicines and traditional services. This was welcomed.
- The limited and haphazard availability, and long-term insecurity, of these non-traditional approaches is an important issue in sustaining this approach.
- CSP in MSK can be challenging for staff, but with training and support practitioners feel they are able to do a good job, and enjoy the appointments, which they describe as beneficial and a good use of their time.

"CSP creates happier teams" GP

• Tailored training in MSK specific issues was needed and proved effective in addressing staff knowledge and confidence. The learning outcomes of a training programme were identified.

### **Practical learning about CSP in MSK conditions**

- We have developed the tools, resources, sample pathways and indicative numbers to enable practices already involved in CSP with other LTCs to include MSK conditions.
- We have established Read/SNOMED codes and a search strategy to identify the three core groups
  of conditions outlined by Versus Arthritis (inflammatory conditions, conditions of musculoskeletal
  pain, osteoporosis and fragility fractures). Indicative numbers are available.
- Since identification from practice records of people living with MSK conditions who might benefit from systematic CSP was time consuming, and because most of these conditions are not included in usual Quality and Outcomes Framework (QOF<sup>2</sup>) recall systems, we have developed a set of instructions for new sites to enable this to be carried out more easily.
- We have developed the tools and resources for people with MSK conditions to be prepared for CSP including information gathering tailored to people with 'MSK only' and those with 'MSK plus'.
- We have explored the use of the MSK-HQ patient-reported outcome measure (PROM) in the
  context of CSP with mixed findings, and observed that most patients and health care
  professionals did not find it gave additional benefit over a generic preparation prompt.
- We have recorded some observations about the use of MSK-HQ and the LTCQ PROM within the routine settings of care used in this study.
- We have explored approaches to ensuring the fidelity of CSP in MSK conditions and commented on evaluation in the context of routine general practice.

### **Learning about numbers**

• MSK conditions are the largest group of LTCs (20% of the population) so the number of people in each practice is large.

<sup>&</sup>lt;sup>2</sup> https://www.england.nhs.uk/publication/2019-20-general-medical-services-gms-contract-quality-and-outcomes-framework-qof/

- Of the three ARUK groups, some people living with inflammatory and fragility conditions are already involved in QOF resourced reviews.
- Pain syndromes (osteoarthritis and back pain), which are two to three times more prevalent, are not included in QOF and currently have little systematic care. They made up 74% of MSK conditions; 15% of people had more than one MSK condition.
- At least half of those living with MSK conditions have other LTCs, and we were able to show how
  issues related to MSK conditions can be included effectively and efficiently in a multimorbidity
  approach<sup>3</sup>.
- Of those people with MSK conditions alone around a third will opt into an invitation to take part
  but there are currently no resources to support CSP for this group. Despite identifying high
  levels of unmet need and satisfaction with the CSP process, practices said that they would not be
  able to continue to offer this to them as it was unfunded work not covered within existing
  incentive schemes.
- As a component of handling workload, it has not been possible to identify those who might benefit
  most from CSP because patient records lack sufficient information on disease 'activity', chronicity,
  severity and the functional impact of MSK conditions. A code for practices to use to indicate the
  potential value of CSP for an individual has been identified but not used systematically. This
  question needs further investigation.

### Learning about transferability and spread

- We have developed a transferable approach to inviting people for CSP in which individual records are reviewed, people are invited to identify their own need for CSP, and non-responders followed up with indicative numbers.
- Even so, this work was only possible because practice teams were already trained and up and running in CSP for other LTCs.
- Despite our guidance which enabled Phase 2 practices to get going more quickly than in Phase 1, layering in the specific MSK issues took longer than expected.
- Because of differences in individual practice processes, definitions of multimorbidity and responses to invitations, it is recommended that practices pilot their recall procedures for 1-2 months to determine workload.
- Facilitation was essential to support the whole team to overcome organisational challenges and ensure fidelity of the intervention during the process of local tailoring.
- In addition to the tools, resources and information developed in the study, all practices needed additional tailored support in the form of
  - MSK/pain-specific training
  - GP support for practice nurses
  - Support to modify IT systems
  - Facilitated problem solving
- The learning outcomes and educational approach for an effective training programme were developed. This included providing information about specific MSK conditions in the context of a CSP approach and the involvement of local specialists to build staff confidence and validate the importance of self-management and community activities.

<sup>&</sup>lt;sup>3</sup> A multimorbidity approach implies that all an individual's conditions / issues are brought together in a single CSP recall process and conversation. The ethos of 'the person not the condition' applies equally to those who may live with only one condition.

# **Chapter 1: Introducing MSK into care and support planning**

### Background, purpose and overview of the study

Joint, muscle and bone conditions are a major cause of pain and disability for people living in the UK, affecting around 20% of the general population and giving rise to 4.6 million general practice appointments per year<sup>4</sup>. Despite this, musculoskeletal (MSK) conditions are barely included within the national incentive schemes for managing long term conditions (LTCs) in general practice which focus on conditions such as diabetes and respiratory disease.

Care and support planning (CSP) is an approach to working with people with LTCs which provides personalised care by replacing tick box reviews with proactive and supportive approaches. In November 2014 Arthritis Research UK (ARUK)<sup>5</sup> published their Report *'Care Planning and Musculoskeletal Health'* which recommended that CSP should be made available to people living with MSK conditions whether alone or alongside other LTCs.

The Year of Care Partnerships (YOCP) study 'Bringing MSK conditions in from the care planning cold - a feasibility study' is a response to this. It was commissioned to work out whether and how this could be achieved and develop specific practical learning to support the recommendations of the ARUK Report.

This study was funded by Versus Arthritis, and directly aligns to their strategic focus to ensure 'no one is living with MSK pain without access to information and support to self-manage'.

This project was a study of implementation rather than a traditional study of impact. It was designed to develop a reproducible approach to CSP for people living with MSK conditions. It was also intended to make recommendations for practitioners and commissioners to enable CSP to become 'normal' care; and for researchers so that exemplars of good practice can be set up as 'laboratories' for future research.

The study was designed in two Phases:

**Phase 1**: to develop and test the specific practical requirements for collaborative CSP to become normal care within general practice for people living with single MSK conditions or who have MSK conditions alongside other LTCs.

**Phase 2**: to test the transferability of the tools and resources developed in Phase 1 to new practices, consolidate the learning and identify issues needing further discussion, clarification and research.

### Care and support planning (CSP)

CSP is about enabling better conversations between people living with LTCs and health care professionals that are focussed on the personal priorities of the individual, so that support and services can be tailored to each person.

<sup>&</sup>lt;sup>4</sup> The State of Musculoskeletal Health 2017, Arthritis Research UK

<sup>&</sup>lt;sup>5</sup> Now Versus Arthritis

CSP has 5 core components (preparation, conversation, recording, actions and review) which all need to be in place for it to be effective. This requires changes to staff attitudes and skills alongside changes to general practice infrastructure.

CSP differs from traditional care. To enable a 'more meaningful conversation' the person is actively prepared to be an equal partner in their care. This includes sending reflective preparation prompts and sharing relevant assessments and test results with the person ahead of a CSP conversation. The health care professional also requires training and preparation for this

Self-management

Non-traditional Community support

Traditional Services

Care co-ordination

Care co-ordination

Time to reflect

2.Conversation and 3.Recording

conversation. Practice systems need redesign to tailor to the CSP process and the specific conditions and circumstances of the individual.

### **Ensuring fidelity**

CSP is a complex intervention requiring changes in ethos, skills and practice infrastructure. This new way of working depends both on both new systems, and also new habits, which can take several months to introduce and embed.

Introducing such an approach requires the core components to be carried out faithfully and to a high standard at the same time as valuing the work that local teams do to tailor these to their particular locality/environment.

Figure 2: Components supporting fidelity of CSP and

Practices selected for the study were afreedly established in delivering CSP to people on their LTC

register but had not formally included MSK conditions in the approach.

We monitored fidelity (Figure 2) in each practice and are confident that all aspects of this including ethos and process were delivered. Each practice adapted the process to their local context but adhered to the key principles and philosophy. While difficult to 'get inside the consultation' and be sure that this is an enabling conversation focused on what matters to the person, patient feedback and the use of Video Enhanced

### The CSP process

**Preparation:** Sharing results/assessments if relevant, preparation prompts and giving time to reflect before the conversation.

**Collaborative conversations:** carried out by a trained practitioner.

**Review:** individualised, discussed and agreed during conversation.

### **Implementation**

**Core CSP elements:** All CSP steps (Figure 1) within a patient focused ethos

**Practices and practitioners:** trained and supported in CSP ethos and approach

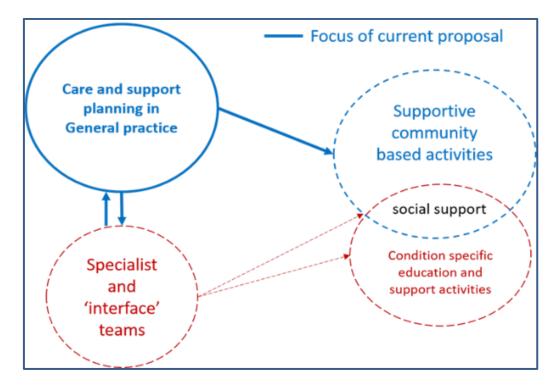
**CSP built into routine clinical pathways:** replaces usual planned care

Observation (VEO), demonstrated that practitioners can and do use a CSP approach for people with MSK conditions.

### Scope of the study

CSP is one element of care and support for people living with MSK conditions. Figure 3 demonstrates the focus of this study was on CSP within general practice and the relationships with system wide MSK pathways.

Figure 3: The scope of the feasibility study



# Chapter 2: How we developed and delivered the study

### **Project organisation and governance**

This is described in the study's Phase 1 Report 'CSP for MSK Phase 1 Report - V1.1 Jan 18'<sup>6</sup>. Also see Appendix Ai for details of the Phase 1 and 2 study team, critical friends and wider engagement.

### Phases and practice recruitment

In Phase 1 (Jan-Oct 2017) we recruited 3 diverse GP practices from the Year of Care Partnerships (YOCP) community of practice using clearly defined criteria and following a structured telephone interview. Each practice had to have established care and support planning (CSP) processes for people with multiple long-term conditions (LTCs), and have trained Year of Care (YOC) practitioners in place. Glenpark Medical Centre in Gateshead acted as the lead practice throughout the study. This practice included the CCG GP lead for IT and supported the guidance on Read codes, searches and integration of resources into the general practice IT systems.

One practice withdrew at the start of Phase 2 (Feb 2018 – Feb 2019) due to the workload involved in a local practice merger. Three new practices were recruited in Gateshead (total 5 practices in Phase 2) using the same criteria as Phase 1 (Appendix Aii). Details of all practices are included in Appendix Aiii.

### How we worked with practices

YOCP coordinated the overall study and worked directly into practices supporting them to implement CSP for MSK conditions, and to share resources and learning. YOCP also supported elements of data collection and captured learning using a schedule of contacts as well as fortnightly/monthly conference calls, ad hoc phone calls and visits linked to supporting practice needs.

Whole study team events were built around the learning needs of the practices, and involved practitioners working with other stakeholders in the design of the study. They included training in specific MSK topics with a focus on delivery within a CSP approach, and provided an opportunity to share and capture learning. They were seen as critical to the success of implementing the approach.

### Approach to evaluation and learning

The Health Research Authority confirmed that the project did not need their approval because it involved service improvement rather than research. We adhered to local Caldicott guidance for the use of patient identifiable data – see Appendix B.

The core aims of the study and objectives of each Phase were refined at 'kick-off' and Phase start/end events. The core team worked with the evaluator, Angela Coulter (AC), who advised on the development of questions and carried out interviews with practitioners and practice teams in both Phases, and with patients in Phase 2.

<sup>&</sup>lt;sup>6</sup> https://yearofcare.co.uk/key-documents

AC attended evaluation meetings and some routine fortnightly practice conference calls, feeding in findings and issues. These were addressed as the study proceeded. The detailed evaluation questions in both Phases are shown in Appendix C.

### Types of data collected

### **Qualitative data:**

Practices completed several qualitative activities. These were:

**Table 4**: Qualitative data collection completed by practices in Phase 2

				Oxford		
	Birtley	Glenpark	Niddrie	Terrace	Teams	Total
Post consultation						
reflection sheet	51	137	8	36	40	
(practitioner)						272
Patient exit						
questionnaires	1	22	0	28	12	63
Video Enhanced						
Observation (VEO)						
consultations	3	4	4	0	2	13
Angela Coulter						
interviews with						
patients	5	5	3	4	2	19
Angela Coulter						
interviews with						
practitioners	2	2	3	1	1	9

Notes of phone calls, practice visits and learning events were also recorded throughout the study.

### **Quantitative data:**

Practices captured quantitative data in two ways:

- 1. Capturing monthly search data to include those identified as suitable for CSP and the number of people invited with and without other LTCs.
- 2. Completion of monthly data collection spreadsheets. Practices completed much of this on an ongoing basis.
  - The burden of data collection for busy general practices was recognised so the collection of referrals, appointments and medication adjustments was limited to two 'intensive data collection' months (Aug 18 and Feb 19 6 months prior to and 5-6 months post the CSP appointment).

We attempted to automate the collection of some data from practice IT systems. However differences in the way data is captured, and the use of the notes fields, meant it was not possible to do this consistently. Instead, practices used their own processes to ensure data was captured for those invited to and attending CSP appointments.

# **Chapter 3: Identifying people with MSK conditions for CSP**

### **Main messages**

- Codes have been identified and a search strategy proposed that enables new sites to identify
  the 3 main groups of MSK conditions (inflammatory conditions, conditions of musculoskeletal
  pain, osteoporosis and fragility fractures) from practice registers, from which to invite people
  for care and support planning (CSP).
- There is little in the clinical record to indicate 'activity' of the MSK condition, functional status of individuals, or who might benefit from CSP.
- Initial searches will identify large numbers, and invitation strategies such as patient selfselection can be used to manage this.
- At least half and up to 2/3 of people with MSK conditions also have other long term conditions (LTCs). These can be included in a multimorbidity approach to CSP with little additional practice resource.
- Of those people with MSK conditions only, around 1/3 will opt into an invitation to take part, despite careful use of language in invitation letters.
- Because of differences in practice processes affecting definitions of multimorbidity and responses to invitations, it is recommended that practices pilot their recall procedures for 1-2 months to determine workload.

### Phase 1

The three practices recruited in Phase 1 were diverse and were already providing CSP to people with LTCs on their registers. The study team worked with the practices to identify the Read codes and prevalence of patients living with MSK conditions in the 3 major groupings identified by Versus Arthritis for inclusion in CSP (inflammatory conditions, conditions of musculoskeletal pain, osteoporosis and fragility fractures). The figures obtained matched national prevalence data where available.

They showed that MSK conditions are coded inconsistently in GP clinical records due to the large number of available codes. The clinical record also contains little functional information, and does not differentiate between ongoing-active and one-off MSK events.

Pain syndromes (osteoarthritis and back pain), which are not included in QOF, made up 74% of the MSK conditions and 15% of people had more than one MSK condition. Between 30-50% of people with MSK conditions at Glenpark Medical Centre also had other LTCs which were already being reviewed as part of QOF processes but without specific attention to MSK components.

Each practice chose a different focus for exploration. One practice, with an exceptionally deprived population, worked to introduce CSP for MSK for people with highly complex 'multimorbidity'. Another focussed on CSP for people living with MSK conditions alone. In all practices introducing CSP unearthed a huge amount of unmet need.

### Phase 2

The focus of Phase 2 was to test the transferability and use of the tools, resources and learning developed in Phase 1 to five practices already carrying out CSP, three of whom had not been involved in Phase 1.

For the purposes of the study people with MSK conditions were divided into:

- those living with MSK alone (MSK only)
- those who also had other LTCs (MSK plus)

New practices were provided with Read codes (Appendix D) and indicative numbers of patients from Phase 1 and a search and birth month recall strategy.

**Table 5**: People with MSK conditions identified (over 6 months) using the search strategy developed in Phase 1 (Gateshead practices)

	MSK only		MSK plus		Totals	
	Indicative	Actual	Indicative	Actual	Indicative	Actual (%)
Birtley	600	327	318	930	918	1257 (137)
Glenpark	360	297	198	275	558	572 (102)
Oxford Terrace	600	285	318	*	918	
Teams	198	137	120	148	318	285 (90)
Totals	1758	1046	844	1353	2399	2717 (109)

<sup>\*</sup>An unplanned reduction in the size of the nursing team reduced the capacity to carry out multimorbidity CSP and delayed the study start.

The data suggests that numbers are dependent on the existing practice recall strategy for people with LTCs. For instance, Glenpark Medical Centre include any of six QOF conditions in CSP. Teams Medical Practice currently offer CSP to those with only two or more of these conditions (in line with a local incentive scheme). Birtley Medical Group routinely recalls everyone with any of 11 LTCs on their register, doubling the percentage of people with LTCs who are offered CSP from 30 to  $60\%^7$ . This is reflected in Table 5 as 102%, 90% and 137% of the indicative numbers provided to these practices.

As a practice includes more conditions in a multimorbidity approach many more people with MSK can potentially benefit from CSP. It seems likely that over half of those with MSK have other conditions which may have an impact on their lives and might reasonably be included in CSP.

This also means that practices wishing to introduce CSP for people with MSK conditions should test definitions of 'multimorbidity', model the distribution of MSK between those currently included and

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<sup>&</sup>lt;sup>7</sup> Newcastle /Gateshead CCG data

not included in CSP, and test recall procedures over a one to two-month pilot period. This will be important to ensure that all those with MSK conditions are included in CSP for MSK only or MSK plus, as well as to indicate practice workload.

The range of conditions involved in CSP is shown in Appendix E and demonstrates that all three MSK condition groups (inflammatory conditions, conditions of musculoskeletal pain, osteoporosis and fragility fractures) were represented.

Table 6 describes the attendance rates for people with MSK only and those with MSK plus. Those with MSK plus were 2-3 times as likely to attend appointments as those with MSK only. If this reflects greater perceived need, it strengthens the argument for inclusion of MSK in CSP reviews for people with multimorbidity.

**Table 6**: Number of patients invited and attended: sample figures from spreadsheets

		MSK only	MSK plus		MSK plus	
	No. invited	No. attended (% of those invited)	No. invited	No. attended (% of those invited)	Total sample size	
Birtley	70	24 (34%)	56	44 (79%)	68	
Glenpark	137	21 (15%)	140	126 (90%)	147	
Niddrie	11	5 (45%)	65	16 (25%)	21	
Oxford Terrace	207	56 (27%)	11	3 (27%)	59	
Teams	54	12 (22%)	114	48 (42%)	60	
Overall totals	481	116 (24%)	386	231 (60%)	355	

The lower attendance rates for people with MSK only have been considered throughout the study. Because there was no functional information to indicate who still had active problems, or who might benefit from CSP in Phase 1, and because of the large numbers with MSK codes, a 'self-selection approach' was developed, with people being invited to 'opt—in'. A sample of people who didn't respond were telephoned and the reasons given for non-attendance are discussed in Chapter 7.

Additional variation in attendance was observed *between* practices in the MSK only group. This may reflect low background attendance rates in Teams Medical Practice and Niddrie Medical Practice, and other practice procedures such as linking attendance with medication reviews or repeat prescriptions.

Adaptations to improve attendance were made throughout the study in line with patient and practitioner feedback. For example we discovered that people in Niddrie Medical Practice associated the words 'care planning' with the 'Liverpool Care Pathway' which related to end of life care, and had received negative press, and so invitation letters needed to be redrafted. In Glenpark Medical Centre people didn't recognise or understand 'fragility'. On advice from the patient user group we

opted to use the words 'joint, bone or muscle conditions' instead of the term MSK which was unfamiliar to most patients.

Our qualitative interviewer summarised the learning around inviting people to CSP:

"The likelihood that patients would accept the invitation and turn up for a CSP appointment seemed to vary according to whether they had prior experience of CSP, whether they were used to attending for regular medication reviews, and whether their appointment was conducted by a doctor or a nurse. Uptake was relatively high where CSP-MSK was linked to reviews of QOF conditions or medication reviews, but it tended to be lower among MSK-only patients."

# Chapter 4: Preparation – the resources and benefits for those with MSK conditions

### Main messages

### Information gathering

- We have worked with MSK experts to develop a routine set of information to be collected during information gathering appointments for relevant MSK conditions (gout and inflammatory arthritis).
- The overlap with other long term conditions (LTCs), e.g. CVD risk, means that MSK tests can be incorporated easily in information gathering appointments and this limits the burden of material to share with patients.
- The lack of a face to face information gathering appointment for those with pain syndromes alone reduces the opportunity to explain the care and support (CSP) process.

### **Preparation material for patients**

- The resources required to support preparation in MSK conditions have been tested for transferability and are now available.
- Patients with MSK conditions place high value on preparation material and time to reflect.
- Preparation material that is sent to the person needs to be simple and not too lengthy/complex.
- A generic prompt which includes MSK issues was preferred to the MSK-HQ by patients and practitioners.

### Impact of preparation on the CSP conversation

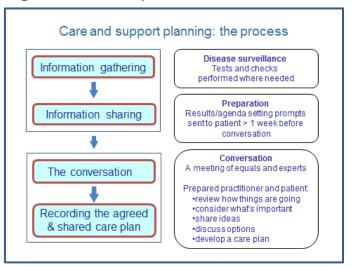
- Practitioners report that people are better prepared and readily participate in discussions.
- Video observation showed all patients used the preparation prompts to highlight what was important to them during the consultation.
- Giving permission to discuss MSK as well as wider topics seemed to be key to raising
  previously undisclosed issues within a CSP conversation, and revealed much unmet need.
- Highlighting CVD risk in gout and rheumatoid arthritis provided opportunities for prevention.

An emphasis on preparation distinguishes the YOC model of CSP from other approaches.

Preparation for the person involves receiving personally relevant clinical information (perhaps collected at an information gathering appointment with a health care assistant), laid out in a specifically designed leaflet with explanations, together with agenda setting prompts for reflection prior to the conversation. For those new to CSP it also includes explanation of the new way of working, and encourages the person's active involvement.

Preparation for the practitioner involves collecting relevant information from all

Figure 7: The CSP process



sources including the clinical record, and arranging for any tests, questionnaires or assessments to be made.

The benefits of a preparation step are:

- Separation of clinical/assessment tasks from the conversation.
- The person has the same information as the practitioner ahead of time.
- The person has time to reflect and share with carers and friends.
- Less time is spent giving information in the CSP conversation meaning more time is spent working things out together.

In Phase 1 we identified that patients valued preparation highly. We developed the resources for preparation for MSK conditions (Figure 8) with input from the local patient group and professional experts as a starting point for new sites.

In Phase 2 practices were able to use these with only minor modifications in the context of both 'MSK only' and 'MSK plus' appointments. This enabled us to learn more about the preparation step itself.

### Figure 8: Preparation resources available

- Condition specific templates to prompt information gathering
- IT populated, condition specific results sharing leaflets
- Generic prompts for those with multimorbidity including MSK relevant 'notice boards'
- Condition specific information leaflets including self-management

### Information gathering

Of the MSK conditions, only gout and the inflammatory arthritis conditions require tests to be carried out routinely and warrant an information gathering appointment. This offers benefits as well as posing challenges within the CSP process.

Compared with most 'QOF groups', CSP for MSK conditions is relatively time efficient, since not everyone needs two appointments. Of those that require condition surveillance, at least half have other LTCs (MSK plus) with similar CVD risk factors, adding little to the information collection time. Patients with rheumatoid arthritis alone are often already attending for drug monitoring that can be

expanded once a year for this purpose. Screening for CVD risk factors in those with gout was new for most practices, and one practitioner commented that this group were now being recognised for the first time, and benefitting from increased awareness and discussion of risk.

On the other hand it emerged that the absence of an information gathering appointment for people with pain syndromes and osteoarthritis reduced the opportunity for face to face explanation of the detail of what to expect and the individual's role within the CSP process. Explanations then took time within the CSP conversation itself, and potentially reduced the time and opportunity of the approach. This might be a particular concern in a person's first CSP cycle.

### **Information sharing and prompts**

Everyone received a 'generic' prompt, printed directly from the practice IT system. This asks open questions such as 'What important issues would you like to discuss?', 'What is important to you?', includes a noticeboard of common issues (medical, social and psychological) to prompt reflection, and invites people to circle any that are important to them. The local patient group advised on MSK topics and these were added to the prompt which had previously been used in CSP for other conditions.

The results sharing leaflets, designed for separate MSK conditions, were also populated directly from IT systems, and had the potential to show trends and add comments. Separate explanatory, condition specific leaflets based around the behaviours that could be modified to make a difference (self-management), were used in a variety of ways. They were sometimes included in the preparation letter to enable the person to start the process of reflection, sometimes handed out at information gathering appointments, and occasionally at the end of the conversation.

The volume of preparatory information was discussed throughout the study. The pressure to include everything at the start of Phase 1 was replaced by learning that "The more you send the less people read". This also influenced the move to drop the MSK–HQ (see below) in favour of the simple generic prompt.

"We found stripping information back to the bare minimum was most helpful" GP

### Patient and practitioner experience of preparation

The positive experiences of preparation identified in Phase 1 were repeated in Phase 2. Of the 63 exit questionnaires completed by patients 81% described the preparatory information as 'very useful', and 16% 'somewhat useful' (see Appendix F). Individuals reported:

"Fantastic. Getting the yellow form made my day. Able to talk about everything I wanted and make plans for better health." **Person with MSK condition** 

"You go to the doctor's usually for a specific reason but there's often something else that you want to mention, but you never get round to it. I just love the fact that this paper asked me how I was coping and more or less asked me what I was doing with my life. ..... And I just love the fact that everything I wanted to say was down on paper, so it was there to be brought out. I just thought it was fabulous!" **Person with MSK condition** 

Even when there were no test results to share the use of a generic preparation prompt helped open up the conversation around MSK issues. In all of the videoed consultations patients used the

preparation documentation to highlight their main concerns, and professionals recognised and valued the chance it gave people to talk about their priorities.

"A person who had lots of issues with her diabetes at this appointment explained that the arthritis in her hands and dependence on tramadol were her main concerns." **HCP** 

"Someone who recently had a total hip replacement and also has diabetes has gained weight due to inactivity whilst recovering from her operation however brought her own completed care plan along with a clear idea of what she planned to do once fully fit again." **HCP** 

"I saw a patient this week who had heart failure however this was 'neither here nor there' compared to the pain in her feet." **HCP** 

"People nearly always started with a story...even if they didn't use or bring the preparation material the story telling told you they'd prepared." **GP** 

### The role of the MSK-HQ

The study was keen to see if the MSK–HQ could be used as a preparation prompt, and as a record of function, as well as an outcome and longer term progress metric. In Phase 1 it was used as a discussion prompt in one practice. In Phase 2 practices were asked to include it together with the generic prompt for the month during which Video Enhanced Observation (VEO) recordings were made, but very few people used these despite having been sent them.

Patients commented "I didn't think much of the questions!" or not reflective of real life "in reality this changes from day to day". The patient user group had a concern that it might be shared with third parties without their knowledge, such as the Department of Work and Pensions.

Feedback from patients and practitioners and the VEO observation supported the use of the generic tool, which included MSK conditions alongside health, psychological and social topics, to enable patients to identify and raise MSK issues.

Practitioners noted that the MSK-HQ didn't raise broader issues to do with the impact of living with MSK on the individual, e.g. finance and social isolation.

"MSK-HQ made people upset when they struggled to complete it – topics are important but maybe not in the way the questions are asked in the questionnaire." **GP** 

The realisation that reducing the burden of material in the preparation step was important for patient engagement. The lack of an IT solution to enable the MSK-HQ to be completed online and directly incorporated into electronic records meant that completing, recording and reviewing it needed to be manual and contributed to a lack of enthusiasm for its use.

# Chapter 5: What goes on in care and support planning conversations?

### Main messages

- Patients and practitioners found care and support planning (CSP) conversations worthwhile
  and valuable. 78% of people reported they could talk about issues that were important to
  them "as much as they needed" and practitioners reported 97% of the conversations as
  worthwhile.
- Conversations were faithful to the ethos and intentions of CSP, and brought together the person and professional agendas around a wide range of biomedical, functional and social issues for people with MSK conditions, with an emphasis on what matters to the individual.
- It has not been clear to what degree MSK topics are routinely covered in multimorbidity conversations. This study has enabled a range of undisclosed MSK issues to be discussed and supported (support for self-management, function, pain, (de)prescribing, links with supportive community/social prescribing).
- Work related issues were rarely raised despite these being included in preparation prompts.
- CSP conversations can be carried out by a variety of practitioners providing they are trained in CSP (and MSK conditions) and are well supported. On average the appointments last around 25-30 minutes.
- Pain was the most common of a wide range of concerns discussed. A lack of clinician experience and confidence in discussing pain was addressed by training.

Phase 1 demonstrated that CSP conversations were valued by both patients living with MSK conditions and professionals. They revealed a huge amount of unmet need across all MSK groups with pain being a prominent feature.

Traditionally the Quality and Outcomes Framework (QOF) focus of reviews has encouraged counting and data collection for those with rheumatoid arthritis or osteoporosis, with little attention to what matters to the individual, and no systematic approach to other MSK groups.

We recorded multiple instances of people highlighting the relief of being able to talk about their MSK conditions and the impact of this on living their life.

"Usually you come in, get tablets, go out. ......you think is this 'it' now? Will I always be like this? It's so helpful to talk." **Person with MSK condition** 

"I've never talked to anyone about this." Person with MSK condition

"The phrase 'opening Pandora's Box' came to mind. Including one 67-year-old woman who never leaves the house, can hardly walk due to problems post-op from a total hip

replacement 9 years ago, and who is absolutely eaten up by anger and resentment that she has been left like this, and had never told anyone how she feels about it." **GP** 

Phase 2 confirmed this.

"..... it's massively appreciated. Patients are used to their joint problems being ignored. There's no doubt it's been of benefit." **GP** 

In Phase 2 we were also keen to explore whether MSK conditions would still get appropriate attention in a 'multimorbidity' CSP conversation, if the person had more than one LTC to discuss (the 'MSK plus' group). We were concerned that MSK issues might be overwhelmed if professionals are more used to, and confident in, talking about other conditions. We wanted to 'get inside' the conversation and make sure that these discussions had a high degree of fidelity to the core principles and values of CSP and that MSK conditions were addressed appropriately.

We used a variety of direct and indirect ways to do this:

- Videoing a subsample of CSP consultations using Video Enhanced Observation (Appendix G)
- The use of post consultation reflection sheets completed by clinicians (Appendix H)
- Exit questionnaires completed by patients (Appendix F)
- Qualitative interviews with patients and staff (Appendix I)
- Feedback at study days

### Describing the new conversation

Taken together these gave us confidence that high quality 'MSK only' and 'MSK plus' CSP conversations were happening, and were helpful and useful to the people that take part in them. They are enjoyed by staff once they have been trained. The feedback from patient exit questionnaires demonstrated that 97% of people felt able to talk about things that were important to them with 100% saying they would recommend CSP for others with similar MSK conditions.

For many, CSP conversations were about topics that people would not otherwise have raised.

"That's the first time I've talked about the pain and loneliness." **Person with MSK condition** 

Understanding their condition supported people to manage it better.

"When I went with knee pain quite a few years ago I was sent for an x-ray. But actually I've got arthritis in my knees. I know it sounds stupid but I didn't realise that. It's really important to know so I can take good care of my joints." **Person with MSK condition** 

"That's the first time I've understood a bit about how my back works." **Person with MSK** condition

For some this was life changing.

"I was scared, I thought if I did any exercise, I might damage myself — I am now going to Tai-Chi and have started to go walking again." **Person with MSK condition**  "She suggested going to the baths and just walking, which I've been doing. It has helped." **Person with MSK condition** 

"Totally thrilled, I have been out of the house by myself for the first time in years." **Person** with MSK condition

### Content of the discussion

CSP enables the person to raise a much wider range of functional and social issues than traditional 'tick box 'reviews. We were keen to ensure that this was also the case in MSK conditions.

**Table 9**: Themes and topics raised in 11 observed CSP conversations (VEO)

Issues	Physical health	Treatment	Social issues	<b>Emotional health</b>
Patient raised	81	80	18	14
Clinician raised	47	116	4	12

This study is the first in which Video Enhanced Observation (VEO) has been used to directly observe and tag what goes on in a CSP conversation. Analysis confirmed that the discussion brought together the concerns of the person living with MSK conditions and the technical expertise of the practitioner (Table 9). Patients raised issues of physical (function), social and emotional health. The professional focus was largely, but not exclusively, on treatments such as medicines, physical activity, nutrition, smoking and weight.

**Figure 10:** Topics most commonly raised on 272 post consultation reflection sheets

- Pain
- Medication (reluctance to rely on pain medication/side effects)
- Coping/living with condition
- Impact on life
- Activity
- Mood
- Weight
- Diabetes
- Osteoarthritis
- Other

The videos demonstrated that people often arrived having circled functional or social issues on their preparation prompt, and this directed the conversation, even though the practitioner was also aware of the MSK focus of the study. In multimorbidity conversations many issues overlapped across conditions, making it relatively easy to incorporate MSK issues.

Clinicians recorded the conversation as being useful and worthwhile on 97% of post consultation reflection sheets and confirmed this at study days. They felt they were able to support people either by listening to them, helping people understand their condition more fully, signposting to community-based activities, or supporting them to think through strategies to live with and manage their conditions better (Figure 10).

Offering Versus Arthritis leaflets was useful when linked to the discussion and issues raised by the individual. For example, explaining the benefits of stretching helped people to decide about making use of community options for this.

### Clinician challenges

At the start of the study clinicians varied in their confidence in discussing MSK issues, and in managing a conversation when there were a number of different problems. One practitioner emphasised the importance of avoiding a template driven approach and focusing on the issues that are most important to the person.

"We bang through the template when they're gone but we capture notes in the patient's words." Nurse practitioner

Experienced practitioners enjoyed being able to address condition specific issues, while having holistic conversations focussed around the issues the person identified.

"I had some medical students sitting in...at the end of the first consultation the student asked what long-term conditions the patient had. This was because the diagnosis wasn't talked about!" Nurse practitioner

However for others professional concerns and lack of confidence in working with people with multiple conditions was an issue.

"Dealing with people with lots of long-term conditions and complex pain problems can be difficult. I sometimes feel a bit out of my depth, especially when we also have to do frailty assessments and reviews. It's easy to get side-tracked when there are lots of different problems to address. I sometimes worry about things I haven't done after the patient has left. It's difficult to ask them to come back. I sometimes feel a bit overwhelmed." Nurse practitioner

The training (Chapter 8) proved critical in building clinician knowledge and confidence and seeing the value of local social prescribing opportunities. Having an involved GP in the practice who could support/mentor nurses was particularly valuable.

### Chronic pain

In Phase 1 pain was the most common issue raised in CSP conversations and in discussions with the user group. This was confirmed in Phase 2 by the VEO videos and post consultation reflection sheets (practitioner).

"...I was feeling a little bit low at the time and just talking to her made me feel better. I have constant pain. I've never been without pain since last year, so it was nice to talk to someone about it." **Person with MSK condition** 

"You struggle on your own and live with pain; you don't bother mentioning it to the doctor as you think there is no point." **Person with MSK condition** 

Pain was rarely mentioned in the clinical record despite analgesics being a common medication. GPs and nurses said they often lacked experience and confidence in talking about and managing it. Handling these issues in the context of CSP was therefore included as a major component of training for staff involved in Phase 2.

This endorsed helping people to understand some of the physiology of pain, the use of simple analgesics, and promotion of strengthening exercises (see Chapter 6). This proved highly effective in increasing clinician confidence and changing their approach to discussing pain.

"I now have a completely different idea of what's involved. For me it has been really beneficial and for the patients I can now present it in a way that's more helpful. Before, I didn't really know what I was offering them. The big thing for me was the realisation that it isn't about getting rid of pain but managing it. As a nurse you want your patients to be pain free, but I now understand that that's not an appropriate goal for chronic pain." Nurse practitioner

"Many people think joint pain is inevitable and will only get worse. Many are told it's wear and tear when they're diagnosed; you're over 50 – quite normal. They think there's nothing much you can do. One of the best things about this project is when people come in assuming they'll get worse and end up in a wheelchair, but you give them information about stretching, weight loss advice, exercise, dance classes, and they go out feeling much better and more hopeful." **GP** 

"Nurses tend to have a 'fix it' attitude – I previously thought that people shouldn't have to live in pain so I'd help them do something about it with pain medication." **NP** 

"Some people come to see me and are clearly crippled with pain but they cope – others with very little pain are not coping and so talking about what matters to the person is important." **GP** 

Clinicians highlighted that they hadn't previously been taught useful strategies, but were now able to include these across all their consultations.

"I'd never go back and not do this now – it filters into general consulting behaviour." GP

This may also be useful for patients to understand earlier in the course of their condition and avoid getting caught in a pain-medication-mobility cycle. In her interviews our qualitative interviewer noted that patients contrasted CSP conversations with previous unhelpful experiences.

# Chapter 6: Impact and resource use

### Main messages

- The positive experience of practitioners and patients in Phase 1 was replicated in Phase 2, including reports of better self-management and behaviour change.
- CSP appears to shift the focus of ongoing support from a medical to a social model of care which was widely welcomed.
- CSP enables better conversations about medicines. This included an overall shift in prescribing
  for pain, away from opiates and high dose NSAIDs, towards over the counter and topical
  options; and more appropriate prescribing for fragility and gout.
- Conversations resulted in greater use of 'non-traditional' community-based activities rather than traditional services (e.g. balance classes, weight management groups, Tai-Chi, Life programme, pop up gyms, attendance allowance and self-management support).

### Patient and practitioner experience and outcomes

Phase 1 reported positive effects of the CSP approach on patient and professional experience, the ability to identify and support unmet need including pain, a person's confidence and capacity to self-manage and use community support. At the end of the study all clinicians said they would choose to go on working in this way, and of those patients completing exit questionnaires, 100% said they were likely or very likely to recommend it to family and friends.

In Phase 2, in depth interviews reported that positive changes extended beyond improved experience alone, translating into better self-management and behaviour change. Both patients and staff seemed to reach a common agreement on the issues and solutions:

"A worthwhile consultation is when the patient leaves feeling empowered, that they have some control over their problems, that I've been able to help by signposting, enabling them to help themselves, rather than here's a prescription for some codeine." **Nurse practitioner** 

"Typically a good consultation is when the patient is open to the idea of self-management and agrees actions they can do. They formulate a need and you have a match for it. Then it's great. Other good consultations are when it becomes clear that they're not coping, often because of mental health issues, weight, and drug use. They just need supportive, unrushed prompts to open up and then you can pick them up. You don't know what they want when they come in, but you're able to offer some kind of support." **GP** 

For some patients the CSP consultation gave them a better understanding of their condition, leading to lifestyle changes.

"I haven't been doing the exercises because I'm not very good at exercising on my own, but I have actually joined a Pilates class as a result of the consultation which I started last night. I do a lot of walking but the particular muscle groups that the doctor said I had to strengthen — I don't think I'm really hitting that muscle group just by walking." **Person with MSK** condition

"I've been doing exercises. They helped tremendously. I still exercise when in the bath — water helps with pain. I do like to go for walks. It hurts but I refuse to give up." **Person with MSK condition** 

Sometimes a discussion with a doctor or a nurse is sufficient to prompt a change.

"She suggested going to the baths and just walking, which I've been doing. It has helped. I look forward to my appointments with her actually." **Person with MSK condition** 

"One patient wanted to lose 5 kilos. "I've done it!" she said. What made the difference? "We agreed it and I didn't want to let you down." **GP** 

"I intended to make sure that I continued with the attitude that you've got a life, live it, and don't spend it in the chair. I don't really know what it was — it was a whole different experience. It was right up my alley because it made me think." **Person with MSK condition** 

Practitioners emphasised the importance of enablement and support, but also stressed the need not to expect dramatic changes, and never to make people feel guilty if they are unable to reach their goals. Small steps can represent great achievements for the person.

"I've seen some positive changes, mood improvements, reversal of trend, starting to do a little bit of walking maybe once a month. One patient came in to say "Doctor I signed up for the triathlon! Go on a bike (no distance involved), walk for five miles in January, and go swimming twice." Fantastic! She failed on the walking but did everything else." **GP** 

"People want to be "heard" they often feel they're neglected when it comes to musculoskeletal conditions." **Evaluator** 

The positive experience for practitioners themselves was emphasised in the end of study days.

"It feels like a new channel of communication has been opened." Nurse practitioner

"After a whole morning of CSP for MSK conditions you really feel that it gives people hope – you come out glowing." **GP** 

We were keen to understand if these initial positive responses were sustained. Clinicians reported positively on repeat encounters with individual patients, and on how the CSP approach supports long term benefits, including for those in disadvantaged communities.

We hoped to learn more systematically from those who were having their second CSP conversation in Phase 2. However, there was not enough overlap in the birth months of those receiving CSP in both Phase 1 and Phase 2, and only 5 patients were reliably identified who had had two CSP consultations (see Appendix H).

"People often have stuck to "plan"/goals and has been life changing." GP

"One patient I saw last year with OA for first CSP came back this year - nothing really needed doing this time BUT they said that what we had done last year had changed their life. It was essentially OT referral/ equipment/ discussing condition etc. - now more independent active and happier." Nurse practitioner

"Many struggle to engage or follow-through with actions from last year however in Niddrie persistence works as eventually people do engage with their health. The problem is that when people have to look after their existence first then health comes second but CSP does make a difference." **GP** 

### Use of medicines

At the beginning of the study some staff had been concerned that inviting people with MSK problems in for a discussion would lead to an increased use of resources, including prescriptions and practice visits.

"Our prescribing lead was initially quite anxious that the project would lead to increased use of painkillers, but that hasn't happened. We've actually done quite a lot of deprescribing. Many patients are pleased to stop taking painkillers." **GP** 

CSP provided an opportunity to discuss and modify medicines, often in relation to pain (Appendix H). Among 272 individuals, prescription analysics including opioids were more often stopped or reduced (17) than started or increased (5). Individuals were signposted to over the counter pain relief or other non-drug alternatives (21). Drugs for gout and fragility syndromes were added for the first time in 5 people.

"We're not reaching for the prescription pad anymore; we're making meds more appropriate and reducing where not helpful" **GP** 

"Asking the question "is the analgesia effective?" has really changed things" **Nurse practitioner** 

It's easier to cope (with pain) if you have good support from primary care. Accuracy of diagnosis is important, appropriate painkillers, advice on painkillers, advice on when not to use them, upper limits, understanding that might have to cope with a degree of pain, getting people off medication. Some are on significant doses because people have been trying to help but end up giving too much morphine. That's been an important part of the clinics." **GP** 

### Service use and referrals

In Phase 2 we planned to learn more about use of resources after CSP. Part of our learning was that within current data collection systems it is not possible to extract appointment and practice resource use reliably.

However, practitioners documented 265 planned actions in 272 post consultation reflection sheets. These included 17 referrals to specialist or intermediate MSK services, and 11 to traditional community services (Figure 11), with advice to self-refer to physiotherapy if required in a further 13. Many people had more than one condition, and it was not always possible to be sure how many referrals (e.g. podiatry) were related specifically to an MSK condition.

In comparison 179 goals and self-management actions were identified, and 45 referrals made to voluntary service and community activities to support these (Figures 12/13).

The issues of low mood (reported on 36 occasions), and the impact of living with the condition (reported on 107 occasions), resulted in frequent signposting to Talking Therapies, Citizens Advice Bureau, LIFE programme, and third sector groups rather than drug modifications (Figure 11).

CSP appeared to shift the focus of ongoing support from a medical to a social model of care which was widely welcomed and has potential benefits for the wider health service.

"In one week, 2 patients I didn't know phoned to speak to me as they had heard I was helping people with pain without using medication." **GP** 

"Enjoyed 'Staying Steady'8- have enrolled for another one." Person with MSK condition

### Figure 11: Referral to statutory services

### Specialist and intermediate care services = 17

Pain team: 2Falls clinic: 1Rheumatologist: 2

• Orthopaedics:2

Tyneside Integrated Musculoskeletal Service (TIMS): 10

### **Community services = 11**

Occupational therapist: 6

District nurse: 1Podiatrist: 4

### IAPTs =10

Talking Therapies Gateshead: 10

### Advice to self-refer if needed = 13

• Physiotherapy: 13

### Figure 12: Self-management goals/activities = 179

Physical Activity e.g. swimming, Tai Chi, walking: 78

Leaflet e.g. Versus Arthritis: 22

Weight including commercial groups: 43

Alcohol reduction: 1

Pain management (self): 33

Return to work: 2

### **Figure 13**: Referral to non-traditional community support = 35

Care navigation: 3 LIFE programme: 9

Citizen's Advice Bureau:4

Befriending: 1

Carers Association: 3

Third sector group e.g. Versus Arthritis: 5

Age UK programme: 4
Other 'social prescribing': 6

# Chapter 7: What we learnt about spread and start up (lessons for implementation)

### Main messages

- This work was only possible because practice teams were already trained and up and running in care and support planning (CSP).
- The practical resources developed in Phase 1 made it possible for practices to set up new processes and systems more easily, but set up time was still considerably longer than we had anticipated.
- Set up tasks involved administration, training in MSK conditions and facilitating practice processes to overlay MSK onto existing CSP processes.
- Facilitation was essential to support the whole team to overcome organisational challenges and ensure the fidelity of the study; all practices made some modifications to the nuts and bolts of what was done but stayed within the ethos and core components of CSP.
- MSK conditions are not routinely included in planned Quality and Outcomes Framework
  (QOF) recall systems and so extending CSP to this group of people is largely not resourced,
  nor a subject of expertise for practice nurses. However our study suggests that potentially
  over 50% of people with MSK conditions might be included in multimorbidity CSP
  appointments.
- At various times during the study currently well recognised pressures such as staff vacancies, organisational change and other urgent priorities interrupted the ability of practices to offer CSP.
- It was rarely possible to predict which individuals might benefit most from CSP.

"CSP is not something you can just roll-out, it's a change in your practice" PM

By the end of the study all 5 practices were successfully carrying out CSP for people with MSK conditions, either as part of multimorbidity ('MSK plus'), or 'MSK only'. Although all practices were already experienced in CSP for other long term conditions (LTCs) as a criterion for taking part, there were significant challenges in including MSK conditions. Those related to organisational issues were successfully overcome by a process of practice facilitation and support delivered by Year of Care (YOC) and by tailored training for health care professionals. However, the high numbers of people with MSK conditions challenged the overall resources available.

### **Organisation and support**

Introducing CSP requires changes in ethos (philosophy), skills and organisational infrastructure. Previous experience from YOCP is that this may take up to 6-9 months and is enormously variable across practices. This study would not have been possible if CSP were not already in place.

In Phase 2, two months were allotted to add MSK conditions using codes, search strategies, IT templates and resources which were provided in a practical manual designed to curate all of the resources developed in Phase 1.

This proved an underestimate of the time required. Two of the three new practices required 3 months, and the third was only completely involved in the last month of the study. The factors (Figure 14) replicated those in other projects<sup>9</sup>, but there were also some specific to MSK.

These included practice organisation and leadership, from both senior clinical and administrative staff and a coherent approach to understanding the nature of the task. Feedback from the practices

# **Figure 14**: Key issues affecting implementation and spread of CSP

- Organisation and leadership
- Confidence in CSP
- Clinical confidence about MSK conditions and multimorbidity conversations
- Coherent understanding of task within teams
- Training
- Facilitation and support
- Mentorship and support within practices
- A strategy to handle numbers

emphasised the importance of seeing the implementation of CSP as a team endeavour. 'In-house' practice sessions ensured that everyone, including administration and clinical team members, could understand the purpose, the process and the detail of their role within CSP.

"There is a whole practice effect in terms of changing language and awareness of care and support planning – it's a ripple effect in terms of previous routines when approaching MSK conditions." **GP** 

"it's important to have admin involved from the very beginning. Someone to keep it moving as part of their job is best." **Nurse practitioner** 

A number of unplanned but critical changes and events within practices affected this, some of which reflect the enormous pressure that general practice is under at present. During the study one practice had to step down because of a local practice merger, the lead practice moved premises and significant changes occurred in the trained practitioner numbers due to staff leaving and joining practices.

### Support provided to include MSK in CSP processes

Practices were supported in a number of ways including formal training, practice facilitation and opportunities to network formally and informally with other practices involved in the study. Training was particularly focused on clinicians and the knowledge and skills they needed to feel confident in discussing MSK issues in the CSP conversation. The wider practice team were involved in kick off events, regular conference calls and study days about the implementation of the study.

Hands on, in-practice facilitation delivered by YOC, which included detailed planning meetings with key practice staff, proved essential to engage the wider practice team, and sometimes had to be repeated to ensure everyone knew their role. These in-house sessions reciprocated learning which was spread to other practices as part of the study.

<sup>&</sup>lt;sup>9</sup> www.yearofcare.co.uk/critical-success-factors

"Because people come and talk about things they (the practice) didn't know they could then start to mention other things." **GP** 

#### Skills

All practitioners identified lack of confidence in dealing with MSK conditions, particularly pain. The clinicians were keen to support people living with MSK issues, and identified use of language, support for self-management and confidence in talking about non-medical solutions as critical elements of learning. These were successfully addressed in training (Chapter 8).

It will be essential for any new site to ensure such training is designed to learn about clinical aspects within the ethos of CSP, balancing knowledge about MSK conditions with supporting people to live with these. Some nursing staff in particular had a steep learning curve and some remained anxious

"It's easy to get side-tracked when there are lots of different problems to address. I sometimes worry about things I haven't done after the patient has left." **Nurse practitioner** 

As a means of addressing this, some practices used a pre-meeting or triage step with a senior practitioner to discuss issues, develop skills and confidence, and provide mentorship.

#### **Numbers and resources**

CSP for MSK is unfunded work for general practice as most MSK conditions are not included in the Quality and Outcomes Framework (QOF).

Practices were provided with additional funding to set up new clinics for those people with MSK who were not already involved in CSP recall. However most practices were running with some vacancies or staff absence, so that even with access to funding, releasing time of experienced staff proved challenging. In many practices CSP involves a minority of staff, further limiting the pool available to provide CSP appointments.

The large number of people with MSK conditions will be a key challenge for spread and wider implementation, and may overwhelm the efficiencies made by including more than half in established multimorbidity clinics. The prevalence of MSK conditions in Phase 1 proved daunting, but the search and triage 'opt in' approach resulted in more manageable numbers in the first cycle of CSP.

In Birtley Medical Group a higher than predicted number of MSK only patients 'opted in' and planned CSP appointment 'slots' were rapidly filled. Rather than make people wait longer after their invitation, they decided to stop sending invitations when no more appointments are available.

"You are only able to do what you can do – so at the end of the month some people won't have been seen due to lack of appointments." **Practice administration lead** 

These vulnerabilities seriously challenge the concept that the beneficial effects of CSP for people living with MSK conditions can be addressed without additional resources in general practice. Following the end of the study, because this is unfunded work, none of the practices involved have been able to continue providing additional CSP clinics to people living with MSK who aren't already included in CSP.

### Understanding who can benefit

The large numbers also raise the question of whether CSP should initially be focussed on those who might benefit most, whether and how these people might be identified, or if CSP might be provided at less frequent intervals. These issues were considered throughout the study and were the subject of a workshop at the final study event.

### Potential solutions to the challenge of high numbers and who might benefit

### Severity of symptoms and condition

In Phase 1, clinicians described the poor quality of information in the clinical record and lack of correlation between the severity of the conditions and experience of living with it ("you cannot predict before someone comes in"). This made identification of those who might benefit almost impossible to gauge in advance and led to the suggestion that people should be invited to self-select; about a third did so.

Practitioners reflected that this was a more 'person-centred' approach than staff trying to decide who ought to be invited, but were keen to ensure that for those who declined this was neither because of poor understanding of potential benefits, nor due to the overwhelming issues of everyday life. Figure 15 gives the main reasons for 'non-response' of those contacted by telephone but does not fully answer the questions around the limitations of self-selection.

**Figure 15**: Reasons given for non-response when the practice telephoned patients

Reasons given for non-response
Didn't receive the letter
Thought I had responded/ intend to respond
Forgot about it
Didn't think it would be useful – no symptoms
Time isn't convenient
Already attend other appointments
Other health issues more significant
Non-specific response

### Nature of the conditions

There was disagreement and so no consensus between practitioners about which conditions to limit CSP to, if this became necessary. All felt that osteoarthritis should be included. Some suggested gout, fragility and fibromyalgia might not benefit as much, but others reported their most useful conversations had been with people with those conditions. The recognition that people with rheumatoid arthritis often attended specialist services, and were already receiving some form of review, also divided opinion.

"Good to be able to incorporate RA discussion in to other LTCS" Post consultation reflection sheet (practitioner)

For many practitioners, CSP had raised the profile of gout and fragility risk within the practice enabling a preventive approach for the first time. It was suggested that everyone with gout should be included, and not involved in self-selection, because risk factor screening for cardiovascular disease was important, and numbers were small.

### **Frequency of CSP**

The high level of unmet need in the first CSP review led practitioners to suggest that subsequent CSP cycles might be less time consuming. Once long-standing health issues had been resolved and everyone was more familiar with the process, CSP appointments might not be needed annually. In a small number returning for a second cycle of CSP this seemed to be the case, but it has not been possible to test this hypothesis properly in the timeframe of the current study.

MSK conditions, like respiratory conditions, have fluctuating symptoms and one important facet of CSP may be to develop contingency plans as well as more formal agreement about review, follow up and repeat. A Read code (2JH) was proposed that might be used to identify those to recall again, but this was rarely used in practice.

# **Chapter 8: Training and support**

### Main messages

- Although most practitioners had already attended Year of Care Partnerships (YOCP) care and support planning (CSP) training there were additional training needs around MSK conditions.
- Practice nurses are trained extensively in Quality and Outcomes Framework (QOF) conditions
  which largely exclude MSK conditions and consequently are often less confident in handling
  MSK topics.
- Practice nurses expressed concern about covering all the conditions people have and also including MSK (navigating a complex conversation).
- Bespoke face to face training sessions (study days) were held as part of the study which increased confidence across all practitioners.
- Having in-practice mentoring/support from a GP (or GP involvement in the conversations) was extremely valuable where available.
- Endorsement of 'more than medicine' approaches by a consultant physician encouraged practice based staff in supporting people to live with, and not just manage, their conditions.

### **Training for MSK specific issues**

All practices had established CSP for people with QOF conditions, and had attended YOCP CSP training. This allowed us to develop training focussed on the learning needs around MSK.

Practitioner input into the learning agenda was based on feedback in Phase 1, review of the post consultation reflection sheets and requests made during the regular telephone calls.

Practitioners had low confidence about some MSK specific issues, especially relating to pain management, and to those conditions usually managed in specialist settings. The QOF framework meant that some conditions (e.g. rheumatoid arthritis, fragility), were usually seen by doctors with a focus on monitoring and drug treatment, rather than what matters to people - living well with these conditions.

Practice nurses who reported that they had had little or no training in MSK conditions especially lacked confidence and some knowledge. Unlike their experience with diabetes (for example), they lacked management strategies for MSK conditions and pain, and had not appreciated options around self-management, management within local communities and supporting people to live well with their conditions.

"The biggest issue is nurses' confidence that they can make a difference to MSK problems. Teasing out the real issues can feel a bit overwhelming in a limited time. Knowing the phrases and questions to ask to enable people to talk about what's really bothering them, and drawing out what's difficult, for example steps, access, transport barriers, also confidence in dealing with particular conditions, e.g. fibromyalgia. I think training in analgesia would be helpful for all, including non-prescribers." Nurse practitioner

Two separate study days of bespoke training were delivered by a local rheumatologist and a specialist pain nurse. The learning outcomes that were specific to MSK management were:

- Have a good grasp of the different MSK conditions included in the study: their aetiology and basic physiology, treatment options, consequences of the conditions and 'red flags'.
- Have developed clear and consistent ways of describing all the conditions to people with MSK conditions (using lay language which promotes a good understanding of the condition).
- Understand drug and non-drug treatments available (across all conditions).
- Have options to support people with a range of symptoms and issues including chronic pain, low mood and anxiety.
- Have a good understanding of mechanisms of pain.
- Have skills around discussing chronic pain and options to support people.
- Have options and skills around making use of 'more than medicine' including a Tai Chi taster session.

#### Impact of the training

Gaining a good basic knowledge of the aetiology, physiology and treatment of MSK conditions was valued. Practitioners also picked out as being particularly helpful:

- Having simple words to describe what is happening in each MSK conditions the use of analogies, stories of what works – being careful with language, and avoiding unhelpful terms such as "wear and tear".
  - "Language is important particularly at the point of diagnosis" GP
- Hearing that specialist professionals could often offer no additional treatment options than those already tried – followed by an endorsement of 'more than medicine' by both the specialist practitioners who were delivering training.
- A focus on non-biomedical treatments, especially of the benefits of physical activity for pain and fatigue, sleep management and reducing social isolation.
  - "The 'Petunias' game cards made people aware of what's out there in terms of local services

     we collated this and used it in practice and on our website." **PM**
- Appreciating that for people with MSK conditions, discussing these often leads to complex and emotionally charged conversations, sometimes coloured by past poor interactions with health care professionals. These are to be expected and strategies for responding to the issues of pain, fatigue and low mood were explored.

Following training confidence scored had risen from 5/10 to 8/10. Clinicians reported that they had moved away from talking about cures and focused more on listening to peoples' stories, acknowledging their own strategies for managing and being more confident to help them develop plans for living well.

"We now talk more about coping rather than treating." GP

"This is not rocket science and you don't need a degree in MSK to do it but people need training to reassure them of this. It's important to manage the expectations of nurses in terms of what's involved." **GP** 

#### **Condition specific learning and chronic pain**

#### Managing pain

Understanding the pain cycle, and the limited number of drugs that are useful in chronic pain, enabled practitioners to see that repeat referrals to specialists and pain clinics were unlikely to provide better outcomes. Reframing pain around exploring ways to live well with pain was very helpful.

"Asking the question "is the analgesia effective?" has really changed things." **Nurse practitioner** 

"We're not reaching for the prescription pad anymore; we're making meds more appropriate and reducing where not helpful" **GP** 

#### Fibromyalgia and fatigue

All clinicians expressed concern about this. The practical session linking this to early childhood experience, anxiety, and disordered sleep, allowed issues around emotions and sleep quality to be explored, and practitioners reported finding this useful to their practice.

"Understanding about sleep deprivation and the effect on MSK conditions was useful." **Nurse practitioner** 

#### Cardiovascular risk

The links with gout and rheumatoid arthritis were new to some and were felt to be neglected areas in clinical conversations, but ones in which general practice clinicians already have skills and experience.

#### **Implications**

In order for the benefits of CSP to become more widely available for people living with MSK conditions practitioners will require MSK specific training in addition to experience of established CSP. It will be important to involve local specialists who understand the context of general practice, the principles of CSP, and can convey the benefits of 'more than medicine'.

The clinicians valued face to face interactive learning grounded in practical application, rather than theoretically driven, didactic approaches. It is expected that pain, fatigue and mood will be key components of any training.

#### Chapter 9: Evaluation dilemmas and further topics for research

#### Main messages

- Overall approaches to evaluation varied in their ease of use and productiveness.
- Data collected by practitioners directly following consultations, simple exit questionnaires completed by patients, and qualitative interviews with patient and staff proved most useful, especially when supplemented by detailed observations from regular teleconferencing and study events.
- Administration of validated paper-based questionnaires to patients and associated return rates have been poor, and so have not been useful to the study.
- The capacity of practices to record and collect new study data consistently, on top of
  everyday work, is limited. The burden on practice staff removed some of the 'joy' of
  delivering the study, and this is an important finding for future evaluations.
- There are a range of unanswered questions which merit further in-depth study as care and support planning (CSP) is introduced more widely for people living with MSK conditions.

The strength of this study is its 'real life context'. A variety of approaches have been triangulated to demonstrate the feasibility and benefits of introducing CSP, as normal care, for people living with MSK conditions. Some of these methods proved more realistic to use, and so were more useful, than others within the systems and pressures faced by general practice. This provides important learning when designing further studies needed to address unanswered questions.

Where data was trapped externally to the practice either via qualitative interviews with the study evaluator or from events, meetings and contacts which were rigorously recorded, a consistent body of learning emerged. The completion of brief post consultation reflection sheets by practitioners at all sites immediately after the consultation proved an important source of information about the scope and outputs of the discussion.

Video Enhanced Observation (VEO) recordings were used for the first time in CSP in this study and, whilst initially practitioners were a little reluctant to be videoed, and sometimes struggled with technical issues associated with using VEO, this provided important confirmatory information about the topics discussed during a CSP conversation. Simple exit questionnaires completed by patients were also useful and have promise if organisational issues experienced in some practices can be overcome.

However, there were challenges over using practice data which would not routinely be collected within the primary care record, and in the distribution and collection of standardised validated paper-based questionnaires. All practices felt that the volume of data collection had been overwhelming. This reduced the 'joy' of taking part in a study which was otherwise motivating and empowering for practice staff. The number of MSK-HQ and LTC-Q questionnaires returned has been low, and meant that analysis would be futile and invalid.

#### Future research topics

This study has addressed the challenge of providing CSP for people living with MSK conditions, demonstrating feasibility and describing the resources, training and practice support needed to

achieve this. It has also brought to the fore a range of new questions about the profile and management of MSK conditions in general practice, how to record and identify need, as well as trying to predict who can benefit most from CSP, and how this can be ascertained. These were discussed at a workshop we ran with Versus Arthritis and representatives from two academic institutions.

A number of these questions might best be answered by an in depth study of MSK conditions and longitudinal follow up within a small number of practices, in parallel with wider implementation and spread of a multimorbidity approach to CSP. The need for much greater support to practices to undertake evaluation as part of such studies is important learning.

#### Recommendations

Care and support planning (CSP) in general practice has the potential to significantly improve the support provided for people living with MSK conditions, designing the support around what is most important to each person and enhancing self-management and community involvement rather than traditional NHS services.

In the light of the findings and successful completion of this study we make the following recommendations.

#### **Versus Arthritis**

- Make the findings of this feasibility study available to people living with joint, muscle and bone conditions, practitioners within the MSK community, policy makers, commissioners and providers.
- 2. Work to ensure that CSP is available to everyone living with MSK conditions.
- 3. Collaborate with other stakeholders to raise awareness of the benefits of CSP for everyone with long term conditions (LTCs), and the advantages of including people living with MSK conditions, within a multimorbidity approach.
- 4. Raise awareness of the low profile, large level of unmet need and lack of resource within general practice devoted to the large group of people living with MSK conditions and pain.
- 5. Work to raise awareness of and improve the management of MSK conditions within general practice including the recording of symptoms, pain and function.
- 6. Develop a training programme with Year of Care Partnerships for general practice staff, which brings together knowledge about MSK conditions and pain, delivered within a CSP approach.
- 7. Support work to identify who can benefit most from CSP, including optimal cycle length and the relationship with local social prescribing opportunities. This might involve
  - a. a longitudinal and in-depth analysis of the current attenders, non-attenders and resource use in this study.
  - b. working with a small number of practices already carrying out CSP and with an interest in MSK conditions.

There are complementary actions by others which would support the findings in this Report including:

#### Policy makers and national commissioners including NHSE

- 1. Ensure that a systematic approach to MSK conditions has similar prominence to other LTCs within advisory and contractual obligations for general practice and that appropriate funding is available.
- 2. Ensure that the specific issues of MSK conditions and pain are addressed within policy guidance on universal personalised care, including CSP.

#### Professional leaders and training bodies including RCGP, RCN, HEE

- 1. Work towards ensuring that MSK conditions are given equal prominence with other LTCs within professional standards and increase the profile of multimorbidity within national training programmes.
- 2. Ensure that training about MSK conditions and pain is designed and delivered within a CSP approach, building in the language and skills to bring together biomedical knowledge and the lived experience of people with MSK conditions.

#### **Local service commissioners**

- 1. Recognise / assess the local prevalence of MSK conditions and associated morbidity.
- 2. Ensure that there is a systematic approach to the ongoing management of MSK conditions within general practice, with a similar profile and prominence as other LTCs.
- 3. Ensure that where CSP is introduced / already happening for people living with LTCs, MSK conditions are included as part of a multimorbidity approach.
- 4. Ensure resource is available to enable those with MSK conditions alone to also benefit from CSP.
- 5. Ensure that there is high fidelity to the core principles and components of CSP as it is introduced; ideally based on the tools, resources, facilitation and learning identified in this study.
- 6. Ensure that local support (training and facilitation) is available to general practice teams to support the introduction and maintenance of high quality CSP for MSK as routine care.
- 7. Ensure that there is a comprehensive range of community activities to support self-management and daily living with MSK conditions ('social prescribing').
- 8. Ensure that there is a comprehensive range of community-based support for people experiencing pain at diagnosis and beyond.

#### **Acknowledgements**

The steering group would like to acknowledge all those who have supported the study:

- Versus Arthritis
- Rebecca Haines, GP and clinical lead for diabetes at Newcastle and Gateshead Clinical Commissioning Group acted as GP Lead to the study team during Phases 1 and 2
- Phase 1 practices and their patients Glenpark Medical Centre, Niddrie Medical Practice and Trinity Health
- Phase 2 practices and their patients Glenpark Medical Centre and Niddrie Medical Practice (who continued from Phase one), also Birtley Medical Group, Oxford Terrace and Rawling Road Medical Group and Teams Medical Practice
- Angela Coulter, Senior Research Scientist, University of Oxford study co-applicant and lead evaluator
- Arthritis Support Group Gateshead
- Wendy Chan, Tai Chi instructor
- ❖ David Gilbert, Patient Director for Sussex MSK Partnership
- Iain Goff, Consultant Rheumatologist, Northumbria Healthcare NHS Foundation Trust
- ❖ Jonathan Haines, Co-Founder, Product & Development Director, VEO
- Rachel Turnbull, Project Manager, Academic Health Science Network for the North East and North Cumbria
- Mandy Wilson, Lead Clinical Nurse Specialist, Pain Management Service, Gateshead Health NHS Foundation Trust (Mandy has now taken up a new role)

# **Appendices**

# Appendix Ai - The core operational project team, critical friends and wider engagement

	Core project team					
Role	Name	Position	Details			
Project Lead	Lindsay Oliver	National Director, Year of Care Partnerships	Lindsay led the project and retained oversight throughout phases 1 and 2			
Co-applicant	Angela Coulter	Senior Research Scientist, University of Oxford	Angela was responsible for qualitative evaluation interviews working alongside the practices and implementation group			
Co-applicant	Nick Lewis-Barned	Clinical lead, Year of Care Partnerships and former RCP Clinical Fellow for Person Centred Care	Nick was the Clinical Lead and provided support for clinical developments			
Co-applicant	Sue Roberts	Chair, Year of Care Partnerships	Sue was a core member of the project team and offered her wealth of expertise in care and support planning			
GP lead	Becky Haines	GP and clinical lead for diabetes at Newcastle and Gateshead Clinical Commissioning Group	Becky was the lead GP throughout phases 1 and 2, providing primary care advice to the project team and implementing CSP for MSK conditions within her own GP practice			
Year of Care Partnerships Project Manager	Lucy Taylor	Operational Support Manager, Year of Care Partnerships	Responsible for coordination and management of all elements of the project			
Year of Care lead trainer	Lesley Thompson	National Trainer and Assessor, Year of Care Partnerships	Lesley delivered training and support to practices and was responsible for elements of qualitative evaluation			

Evaluation team	Toby Knightley- Day <sup>10</sup>		Managing director of Fr3dom Health (a provider of patient experience solutions)	Toby will be part of the evaluation team, led by Angela Coulter, and will use the Fr3PROMS platform to deploy the MSK-HQ and LTCQ PROMS	
			Critical Friends		
Sarah Cowling	(	Chief Ex	ecutive, HealthWORKS N	lewcastle	
Sarah Clarke	1	Health S	ervices Improvement Ma	anager, Versus Arthritis	
Kate Croxton	1	Head of	Professional Engagemen	it, Versus Arthritis	
Benjamin Ellis	!	Senior C	linical Policy Adviser, Ve	rsus Arthritis	
Liz Lawrence	1	Head of	Health Service Improver	nent, Versus Arthritis	
Wealds			GPwSI MSK Medicine, Clinical Lead for MSK Medicine High Wealds, Lewes and Havens CCG, Vice President of British nstitute of Musculoskeletal Medicine		
Primar			Senior Lecturer in General Practice at the Arthritis Research Primary Care Centre, Keele University and GP in NHS Manchester		
Nadine Clark and En	nma Hilary	People I	iving with MSK condition	S	
		W	ider engagement		
David Gilbert	1	Patient	Director for the Sussex M	1SK Partnership	
Arthritis Support Grateshead with 30+	•	The grouproject.	e group has provided ongoing advice and support to the oject.		
Dr Iain Goff		Consultant Rheumatologist, Northumbria Healthcare NHS Foundation Trust			
		Co-Founder, Product & Development Director, Video Enhanced Observation			
Jonathan Harness		GP and Chief Clinical Information Officer, Newcastle Gateshead CCG			
Dr Rachel Turnbull		Project Manager, Academic Health Science Network for the North East and North Cumbria			
-			Clinical Nurse Specialist, Pain Management Service, nead Health NHS Foundation Trust		
		(Mandy	has recently left the serv	rice to take on a new role)	

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 $<sup>^{10}</sup>$  Toby Knightly-Day sadly died unexpectedly in July 2017.

Wendy Chan	Tai Chi instructor who delivered a Tai Chi session to the study
	team during one of our learning events

# **Appendix Aii** - Criteria for selecting practices from expressions of interest for MSK study

- Must be leadership within practice / across community (demonstrate track record)
- Must be doing CSP with fidelity to original principles themselves and leading it /championing it
- Must have been on YOC training
- Practice must be doing or moving towards multimorbidity
- Must be prepared to work on all those with MSK on register, not just as one component of multi morbidity
- Must be prepared to work on developing new tools
- Must be prepared to work directly with YOCP, and evaluators
- Flexible approach to whole things –design, change, making it work and review of processes
- Must have at least blessing of local MSK community and understand how it fits with any local plans / pathways

# Appendix Aiii - 'Bringing MSK conditions in from the care planning cold – a feasibility study'

#### **Practice profiles**

Phase 1 – three GP practices

	Glenpark (Phase 1 & 2)	Niddrie (Phase 1 & 2)	Trinity
Practice population	9187	3366	11611
Location	Gateshead, inner city	Edinburgh, inner city 'deep end' practice	Buckinghamshire, rural
Ethnicity estimate	1.9% South Asian, 1.7% other non-white ethnic groups	Over 90% white British or European, large proportion of Polish and African refugees amongst the ethnic minorities	Mixed community, almost all white British
Local issues	Deprived community with deprivation quintile 5	In 2014 92% of the practice population were in the 15% most deprived of the Scottish population	Almost all deprivation quintile 1 however rurality and service access cause issues
Type of record system	EMIS Web	Vision	EMIS Web
Previous experience of CSP	Glenpark began offering CSP for people with CVD, DM, respiratory conditions and COPD (single condition and multimorbidity) in 2015. This totalled around 800 patients.	CSP was introduced in late 2016 with a person centred rather than disease-focused approach for all long-term conditions which totalled approximately 1,500 patients.	Trinity introduced CSP in 2015 for conditions as follows: CHD,HF,CCA/TIA, COPD, Diabetes, Mental health, Dementia, CKD, AF, PAD, RA, Hypertension and Asthma Covers about 2100 patients taking into account co-morbidity
Other points to note	Dr Becky Haines is the lead GP for this project. Dr Haines is also a Year of Care trainer following successful completion of the Train the Trainers course in 2015.	Dr Roland Baumann is a supporting GP for this project. Dr Baumann has attended Year of Care care and support planning core training.	Dr Stuart Logan is a supporting GP for this project. Dr Logan has attended Year of Care care and support planning core training.

Phase 2 – Trinity withdrew from the project however three new practices joined

	Birtley	Oxford Terrace	Teams
Practice population	16,050	15,734	5,526
Location	Gateshead, inner city	Gateshead, inner city	Gateshead, urban
Ethnicity estimate	1.3% Asian	1.1% mixed, 3.5% Asian, 1.0% Black, 1.2% other non-white ethnic groups	1.2% mixed, 3.6% Asian, 1.2% Black, 1.0% other non-white ethnic groups
Local issues	Fifth most deprived decile	Third most deprived decile	Second most deprived decile
Type of record system	EMIS Web	EMIS Web	EMIS Web
Previous experience of CSP	Introduced for multimorbidity and single conditions in 2016 covering: Diabetes COPD CHD Heart failure, Stroke/TIA Hypertension Asthma CKD AF PAD	The practice started multimorbidity and single condition CSP as a pilot practice for the enhanced service around 2013/2014. This covered the chronic diseases as per QOF: Diabetes Hypertension CHD/IHD Stroke/TIA COPD Asthma AF Heart Failure	Introduced care and support planning in 2016 for any patient with 2 or more conditions, one of which was diabetes, CHD or stroke.
Other points to note	Liz Bryant is a Year of Care trainer and works as Nurse Practitioner at Birtley. Liz has been supported by Dr Jeremy Watson.	Dr Tasneem Rana is a Year of Care trainer and is a GP at Oxford Terrace. Oxford Terrace spans across two locations in Gateshead – Oxford Terrace and Rawling Road.	Michelle Anderson is a nurse practitioner at Teams and is the practice lead for CSP, supported by business partner Sue Jennings.

### **Appendix B** - Patient Identifiable Data – Caldicott Security Instructions

For the feasibility study we expected that some patient identifiable data in the form of NHS numbers would pass between the GP practices involved and Year of Care.

The patient identifiable data was NHS numbers which were captured on some of the data gathering documents. Having the NHS number on the data gathering documents meant we could carry out an in-depth data analysis on a patient by patient basis where required.

The Caldicott Team at Northumbria Healthcare NHS Foundation Trust approved our proposal form with a number of instructions. They are listed below:

- 1. No patient identifiable information is to be stored on a laptop
- 2. No patient identifiable data is to be stored on any removable media for example CD, floppy disc or USB unless it is encrypted using Trust Approved WinZip v11 only
- 3. Patient identifiable data must be stored on the Trust secure drives i.e. H, X and Y as these are the most secure storage facilities
- 4. No identifiable information can be used in any reports, publications or presentations
- 5. Personal identifiable information can be emailed, using your Trust email account (@northumbria-healthcare.nhs.uk) to a recipient who also has a Trust email account (@northumbria-healthcare.nhs.uk)
- 6. Personal identifiable information can only be sent using your Trust email account to non-Trust email accounts if the data is encrypted using WinZip v11 only
- 7. Personal identifiable information can be sent via NHSnet email service so long as both the recipient and the sender have NHSnet email accounts (this email service uses approved encryption)
- 8. All bulk personal identifiable information is to be sent via the Trust approved secure courier only

### Appendix C - The overall aims of the study and evaluation questions– phase 1 and 2

In phase 1 YOCP worked intensively with three general practices to identify the key issues involved in establishing CSP for people living with MSK conditions. YOCP worked with an additional two GP practices (five in total) during phase 2 to test the transferability of tools and resources developed and investigate further the issues raised in phase 1.

#### The aims of the study shaped phase 1. There were 5 main aims:

- 1. Establish the scope and content of a general practice MSK register for recall for CSP and develop practical guidance as to how to set this up on the three common GP IT systems (EMIS, SystmOne, Vision)
- Work out how the tests and assessments needed for disease surveillance for MSK conditions can be incorporated into the role of a health care assistant at a preparatory visit and what IT support is needed
- 3. Work out how preparation works for people with MSK conditions for the process and for the conversation (with and without results sharing), and test the ARUK MSK-HQ and other potential tools
- 4. Work out the training needs of staff who deliver CSP for people with MSK conditions
- 5. Run CSP for 3-6 months and maximise learning to make any appropriate modifications

### During phase 1 the aims were met however we also determined the evaluation questions that we attempted to answer during phase 2. They were:

- 1. Can we provide detailed guidance on the relevant codes for the 3 main groups of MSK conditions to generate a potential invitation list on all three IT systems?
- 2. Who can benefit from CSP? How can we identify them and record this?
- 3. What are the best preparation prompts for the person in single MSK condition and multimorbidity contexts?
- 4. What are the best professional information gathering prompts (in addition to tests and tasks) for use in the conversation and to include in record?
- 5. What is the role of MSK-HQ and LTCQ in MSK (and other CSP) contexts? How to use as PROMS?
- 6. What goes on in the single condition and multimorbidity conversation?
- 7. What is the overall (and components of) training staff need to be involved in CSP for MSK?
- 8. What are the issues about pain that this project needs to report on? What should be the scope and outputs for phase 2?
- 9. How to describe the role of and links with local specialist services in CSP? What should phase 2 report on / recommend?
- 10. How to describe the role of, and links with, supportive community activities in CSP? What should phase 2 report on / recommend?

### Appendix D - Read codes for MSK conditions for recall

Individual condition within group	Codes for searches
Inflammatory conditions	
Rheumatoid arthritis etc.	N04%
Inflammatory spondylopathies	N10%
Gout & other crystal arthropathy	N02%, C34%
Psoriatic arthropathy	M160%
Arthropathy in Crohns disease	NO311
Connective tissue disease	N00%
Conditions of musculoskeletal pain	
Osteoarthritis	N05%
Back pain and non-specified	N11%, N12%, 16C%, N14%
Fibromyalgia	N239
Osteoporosis and fragility fractures	
Osteoporosis	N330%
Fragility fractures	N331N

<sup>\*</sup>Identifying the above codes for recall from a list of 500 potential Read codes was carried out in Phase 1.

### **Appendix E** - Attendees by MSK condition

This data was recorded during the intensive months of data collection in Phase 2 and demonstrates that people with all of the MSK conditions included in *'Bringing MSK conditions in from the care planning cold – a feasibility study'* were involved in CSP reviews.

Condition	Number invited	% of those invited with the condition	Number attended and seen in CSP	% of those invited who attend	Total % of those with condition who were seen in CSP
Rheumatoid disease	41	11%	22	54%	10%
Inflammatory Spondyloarthritis	17	4%	8	47%	3%
Gout	55	14%	36	65%	16%
Connective Tissue Disorder	0	0%	0	0%	0%
Osteoarthritis	231	60%	157	68%	68%
Back Pain	113	29%	90	80%	39%
Fibromyalgia	8	2%	5	63%	2%
Osteoporosis/Fragility	61	16%	42	69%	18%
CVD	89	23%	69	78%	30%
Diabetes	119	31%	86	72%	37%
COPD	83	22%	56	67%	24%
Conditions	386		231	60%	

#### Appendix F - Exit questionnaire data

To support the qualitative patient evaluation as part of the feasibility study 'Bringing MSK in from the care planning cold' the project teams developed an 'exit postcard' to be given to patients immediately following their care and support planning conversation.

Below are the results from the 63 postcards collected by the practices.

Number of patients postcards completed:

Teams	Oxford Terrace	Glenpark	Birtley	Niddrie
12	28	22	1	0

Q1 - How useful wa	as it to get informatio	n before today's appoin	tment?	
				Did not
Not at all	Not very useful	Somewhat useful	Very useful	read
1	1	10	51	
Q2 How much did	you get the chance to	talk and think about the	e issues that were impo	ortant to
you?				
	We touched upon		As much as I needed	
Not at all	these issues	Quite a bit	to	Don't know
1	1	12	49	
Q3 If you had a frie	end or family member	with the same conditio	ns as you have, how lik	ely would
you be to recommo	end this way of working	ng (care and support pla	anning) to them?	
		Neither likely or		
Extremely likely	Likely	unlikely	Unlikely	Don't know
43	20			

#### Comments noted by patients on the postcards:

#### **Oxford Terrace and Rawling Road Medical Group**

- I felt relaxed and able to talk freely and not rushed
- Great Dr who has the time to listen
- Dr Rana is a lovely doctor she is the only one that listens, would only go and see her
- I have researched my condition extensively however extended appointment with pointers would be good for others who haven't
- Dr Rana was so lovely and helpful and made me feel so much better from her help, thank you

- It was so refreshing to be able to speak about all the things that I needed to without feeling I was being a nuisance it was a relief to have the time to discuss my concerns
- Very helpful consultation which addressed underlying issues and I have follow-up actions which I
  am very grateful for, thank you
- Lesley was very helpful and offered suggestions for alternative treatments
- Because it is a rain check 30 minutes time out to consider and advice is targeted so nothing unnecessary discussed
- The visit was very helpful and informative
- Feel very confident speaking with Dr Rana, she has helped me a great deal and have been given lots of advice and help love Dr Rana, feel so comfortable with her, many thanks
- I know what the pain is
- Very good
- I am happy with the doctor and she listened to me

#### **Teams Medical Practice**

- Got on well with nurse, very informative.
- Michelle was a great listener and very helpful
- I found the appointment very useful
- It would give them the chance to discuss options open to them
- The nurse spoke to me so I could understand everything she said, very grateful
- Good advice, able to try more recent medication

#### **Glenpark Medical Centre**

• Fantastic. Getting yellow form made my day. Able to talk about everything I wanted and make plans for better health.

#### **Birtley Medical Group**

• There are things that bother you at home and you don't know how to find out about them

The patient exit questionnaire is included overleaf.

### Thank you for your feedback

Please complete and put in the box at reception.

Your views are really important to us.

©Year of Care V1.0 Apr 18

Please take a couple of minutes to answer the three questions below by circling your answer.

How useful was it to get information before today's appointment?

Not at all useful

Not very useful

Somewhat useful Very useful Did not read

How much did you get the chance to talk and think about the issues that were important to you?

We touched

Not at all

upon these

Quite a bit

As much as I needed to

Don't know

If you had a friend or family member with the same conditions as you have, how likely would you be to recommend this way of working (care and support planning) to them?

Extremely likely

Likely

Neither likely or unlikely

Unlikely

Don't know

Please say why you gave that score

⊚ rear or care 2019

### **Appendix G** - MSK Topics in Care and Support Conversations Using Video Enhanced Observation (VEO)

VEO was developed in The Department of Education at Newcastle University as a means of providing structured objective observations of lessons and teacher/pupil interactions. The VEO tool also enables a practitioner to video their practice and to tag specific actions, behaviours, skills or interactions they are interested in, either during videoing (by a mentor or supervisor) or by uploading the footage securely for tagging by themselves or a third party.

In this project we used VEO to allow the team to review:

- 1. The topics raised by professionals and by people living with MSK issues
- 2. The impact of preparation on the consultation in particular the pros and cons of using a generic versus MSK specific prompt

In addition we were able to see the style of delivery of the consultations and confirm that they were in keeping with care and support planning (CSP). 11 videos captured using VEO were submitted by practitioners participating in the study and reviewed by the Year of Care team. We had aimed for a total 20 videos using VEO but it was noted that some practitioners had technical difficulties and one practice chose not to submit any videos (it was optional to allow opt-out if anyone was uncomfortable with videoing consultations).

VEO encourages users to capture data about the video and subject before recording and we tailored the form to be specific to the project. Unfortunately none of the practices completed the pretagging data set fully, even though instructions and support were provided. Despite the challenges, having access to real CSP consultations was invaluable for the study.

#### **Findings**

#### 1. The topics raised by professionals and by people living with MSK

	Physical health	Treatment	Social issues	Emotional health
Patient	81	80	18	14
Clinician	47	116	4	12

Pain and treatment (in terms of coping) were the main topics raised by the patient. The patients were enabled to talk and share their concerns in all of the videos. This was facilitated by the CSP consultation process encouraging responses using open questions and exploring issues.

As expected, patients usually raised social issues known to them including issues in relation to activities of daily living, social isolation and worries about being dependant. People frequently expressed emotions such as frustration, anxiety and low mood often related to the worry over 'lack of independence' now or in the future and how they will manage and cope. Sleep and fatigue were also issues often raised by patients but not always responded to by clinicians.

Health care professionals were more likely to raise treatment options which included not only pain management, but treatment through activity and lifestyle.

### 2. The impact of preparation on the consultation – in particular the pros and cons of using a generic versus MSK specific prompt

The generic Year of Care preparation prompt (sent to patients ahead of the CSP conversation with test results where relevant) was used in 4 out of the 5 practices and seemed to enable some people to identify and consider MSK and non MSK issues. MSK issues were fully explored in all of the conversations, usually with the patient commencing the conversation with their main MSK thoughts and issues.

3 of the 4 health care practitioners introduced the conversation with an overview of the MSK project and used the generic Year of Care preparation prompt.

1 of the 4 practices had shared the MSK-HQ with the patient ahead of the consultation and referred to it during the conversation. This focused the consultation on symptoms only and so the practitioner then used the generic Year of Care preparation prompt to create a broader understanding of the person's life. In this practice the health care practitioner used the MSK-HQ as a tool to support exploration of concerns. The other health care professionals found that the MSK-HQ limited consultations as it focussed only on symptoms, however treatment and impact on physical and emotional health are important issues raised as we have seen throughout the videos.

"It's hard to complete as my symptoms change on a day to day basis" **Patient Quote on MSK-HQ** 

#### Overall reflections from video of CSP consultations captured and reviewed using VEO

- Pain and medication were the main (or one of the main) issues raised in all of the conversations.
- MSK conditions can often affect a number of aspects of life managing day to day activities of living, impact on day to day coping, and in a number of the conversations sleep was identified as a major issue.
- MSK conditions affected all aspects of people lives, but people with MSK conditions seem
  resilient and find a way to cope, often with limited use of medication. They appear to use a
  range of non-traditional support and activities which they have discovered themselves that
  appear to work.
- People with MSK don't appear to expect 'cures' from the consultation and don't expect to be seen by health care professionals.
- People with MSK conditions appear to value the chance to discuss their concerns and issues with health care professionals and be listened to.
- In the conversations, it appeared that it was relatively easy to incorporate MSK issues and concerns in to a multimorbidity conversation. A number of the issues and concerns overlapped across conversations

## **Appendix H** - Post consultation reflection sheets (practitioner) – summary of findings

#### **Purpose**

As part of our qualitative project evaluation we requested that clinicians capture reflections and information from their conversations with patients immediately after the consultation.

Health care professionals (HCPs) were asked to complete 'post consultation reflection sheets' (see below) designed by the project team to collect length of appointments, patient concerns, the main topic of conversation, goals and outcomes, and professional issues.

During phase 2 we identified that we had missed the opportunity to collect information about the impact of Year of Care preparation materials shared with patients ahead of their consultations. This heading was added in order to capture clinician's thoughts on the impact of preparation.

HCPs were also asked to consider if they thought the consultation had been worthwhile.

Practice patient no.			1 <sup>st</sup> or 2 <sup>nd</sup> review	
Duration of consultation (mins)	Allocated		Actual	
What was impact of the		1		1
preparation prompts on the				
consultation?				
Main concerns raised				
Topics discussed				
·				
Was this a worthwhile				
consultation?				
Consultations				
Professional training issues				
identified				
Goals and actions (include				
referrals)				
	Related medi	cation changes		
	Related socia	prescribing		
		. p. 2001.011.18		

Numbers of post consultation reflection sheets reviewed

272 post consultation reflection sheets were completed by health care professionals and collated by Year of Care.

Practice	Birtley	Glenpark	Niddrie	Oxford Terrace	Teams	Total
Total A5 reflection sheets completed	51	137	8	36	40	272

#### **Summary of findings**

We report below on the data collected and our findings. Not all of the fields on the post consultation reflection sheets were completed every time.

#### Appointment length

The appointment length allocated and actual appointment durations were recorded on 267 of the post consultation reflection sheets. We found that where a 20 minute appointment time was allocated around 70% ran over time for an average of 9 minutes. Where a 30 minute appointment time was allocated however around 60% ran under for an average of 6 minutes.

The optimum appointment duration to allocate for the CSP conversation therefore appears to be 25 minutes.

Preparation prompts shared with patients ahead of the care and support planning (CSP) consultation

- All post consultation reflection sheets reported that the Year of Care preparation prompts, when used by patients, were positively received
- Quotes extracted from the post consultation reflection sheets demonstrated that this aspect of CSP was well received by patients and had a useful impact on the consultation:
  - "Patient was aware what the appointment was about and had a chance to think about questions"
  - "Patient had thought about questions to ask"
  - "Patient liked preparation felt it allowed joint discussion"
  - "Patient looked at results and had changed diet and exercise already"

#### MSK-HQ/LTCQ

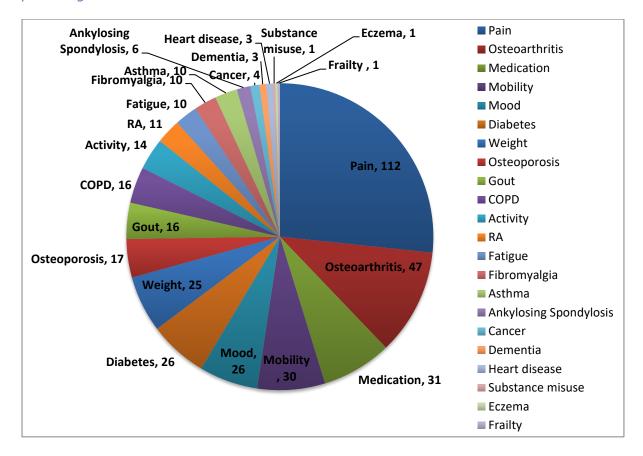
- Some of the practices sent patients either the MSK-HQ or LTCQ questionnaire as part of the preparation material in order to evaluate their usefulness as preparation prompts for patients
- In total 10 MSK-HQ and LTCQ questionnaires were completed and brought back to the consultation, however few patients found the resources helpful as a preparation tool
- One HCP found them on occasion to be a helpful professional prompt to start the conversation

- Comments on the MSK-HQ and LTCQ questionnaires captured by health care professionals and patients were:
  - "Didn't influence consultation" Health care professional
  - "Person had not engaged because they were coping well" Health care professional
  - "Didn't think much of the questions" Patient
  - "Really difficult to complete" Patient
  - "I completed it, but it's difficult, it varies on each day" Patient

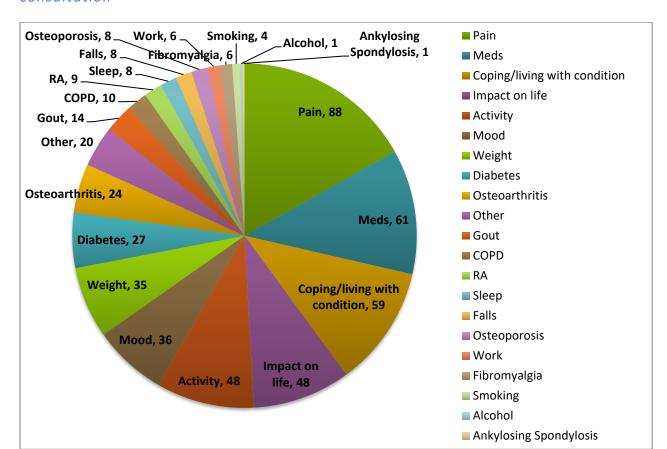
#### Concerns raised and topics discussed

Figures 1 and 2 demonstrate both the main concern raised initially by the patient and the range of topics introduced and discussed during the conversation.

**Figure 1** - Main concerns raised by patients during the care and support planning consultation



- Pain was the most common concern identified by patients followed by osteoarthritis (often relating to symptoms of the condition), medication, mobility, mood and weight.
- Although not the commonest condition raised, gout appeared to raise most questions and to previously have been least understood.
- Patients brought a large number of non MSK issues to the consultation some medical, some social and some psychological.



**Figure 2** - Main topics discussed during the care and support planning consultation

- Pain was the main topic raised often aligned with medication. However the conversation has led to a discussion around coping with the condition, its impact on life and the benefit of activity.
- Whilst medication was often discussed there was very little new prescribing (see medication table) and activity was by far the most common goal/action.

Was this a worthwhile conversation?

248 (97%) of the post consultation reflection sheets stated that the consultation was worthwhile (excluding those where this was not captured).

Yes, worthwhile	Not sure	No, not worthwhile	Not captured	Total
248	3	5	16	272

Professionals cited their reasons for finding the consultation worthwhile as:

- "Because of reassurance and listening to concerns"
- "Able to help answer some of the patients concerns and enable him to talk about his issues/concerns"

- "New information"
- "Reinforcing the impact of keeping active"
- "A chance to discuss staying safe and preventing falls"
- "Supporting strategies for pain relief"
- "Good to be able to incorporate RA discussion in to other LTCS"
- "Patient enjoyed being part of the care and support planning process"
- "The person had thought they shouldn't bother the clinician with their OA but they are so glad to talk"
- "Patient expressed extreme satisfaction with discussion"
- "Patient seemed very happy with the outcome"

Patient quotations were also captured by clinicians on some reflection sheets:

- "I was told that I would need a knee replacement years ago and I am still happily on my old ones"
- "A revelation"
- "All these years (25-30) and no one's even bothered about my arthritis"
- "People don't see arthritis, they don't know it's there, you think it's a normal part of ageing so you get on with it"
- "This is brilliant what an excellent idea"
- "You have proved me to be an old fool, this way really helps"

Those who recorded a 'no, not worthwhile' response gave the following reasons:

- "Patient has own coping strategies"
- "Recently seen a specialist so this was a duplication of appointments"
- "No pain and under rheumatologist"
- "Often less useful for RA when the patient is seeing a specialist"
- "Miscoding and no MSK conditions present"

#### Training needs identified by health care professionals

There were some training needs identified on the post consultation reflection sheets:

- Osteoarthritis and its effect on day to day activities
- Managing osteoarthritis that only affects hands
- Benefits of x-rays in lower back pain
- Management of frailty and fractures
- Need to review osteoporosis guidelines in relation to treatment guidance
- How long to give colchicine for
- Frailty index scoring
- Addressing multiple conditions in one appointment i.e. OP, OA, AF, Stroke, PVD, COPD
- Complexities of patient medication and conditions (post pain clinic opioids plus other analgesia)
- Gabapentin debate and related issues
- Know more about spondyloarthropathy x 2
- Role of exercise in each condition
- Side effects of methotrexate

- Osteogenesis imperfecta
- Helping someone who refuses to alter meds

It was noted in the analysis that some health care practitioners did not discuss 'more than medicine' approaches but appeared to focus on traditional methods of treatment for patients. This issue was picked up during training.

Goals and actions

Of the 272 post consultation reflection sheets collected:

#### Referral to statutory services

#### Specialist and intermediate care services = 17

Pain team: 2Falls clinic: 1Rheumatologist: 2Orthopaedics: 2

• Tyneside Integrated Musculoskeletal Service (TIMS): 10

#### **Community services = 11**

Occupational therapist: 6

District nurse: 1Podiatrist: 4

#### IAPTs =10

Talking Therapies Gateshead: 10

#### Advice to self-refer if needed = 13

Physiotherapy: 13

#### *Self-management goals/activities = 179*

Activity e.g. swimming, Tai Chi, walking: 78

Leaflet e.g. Versus Arthritis: 22

Weight including commercial groups: 43

Alcohol reduction: 1

Pain management (self): 33

Return to work: 2

#### Referral to non-traditional community support = 35

Care navigation: 3 LIFE programme: 9

Citizen's Advice Bureau: 4

Befriending: 1

Carers Association: 3

Third sector group e.g. Versus Arthritis: 5

Age UK programme: 4
Other 'social prescribing': 6

Medication	Stopped	Reduced	Increased	Added
	Prescribed			
Bone protection				
Alendronic acid	2			1
Calcium and vitamin D				1
Gout prevention				
Colchicine	1			1
<ul> <li>Allopurinol</li> </ul>			2	2
Pain relief/mood management				
Tricyclics				
Amitriptyline	2	1		2
Duloxetine			1	1
Nortryptiline				1
SSRI (for mood)				1
Sertraline (depression)	1			
Pain syndromes(opiates)				
<ul> <li>Opiods (non-specific)</li> </ul>		5		
Oramorph		1		
Morphine		1		
MST	1			
Cocodamol	1			2
Codeine	2	3	1	2
Codydramol	1			
Tramadol		2		1
Non-steroidals				
Etodolac				1
Naproxen		2		4
Nefopam	1			
Piroxicam				1
Membrane stabilisers				
Gabapentin	1	1		1
Pregabalin			1	
Miscellaneous				
Diuretic (for falls)	1			
Steroid injection				1
Total (% of 272 post consultation reflection sheets	14 (5%)	16 (6%)	5 (2%)	23 (8%)
completed)	(3.1.)			
	Over the counter			
Paracetamol		2	1	5
Ibuprofen	1	1		2
Analgesia (non-specific)	1	1		1
Topical gel	1			12
Capsaicin cream				1
Total (% of 272 post consultation reflection sheets	3 (1%)	4 (1%)	1 (<1%)	21 (8%)
completed)				<u> </u>

Patient quotes – relating to goals and actions on the post consultation reflection sheets

- "Back pain was ruining my life"
- "Enjoyed staying steady- have enrolled for another one"
- "Doesn't take painkillers- feels like a walk normally settles pain"
- "I used to walk miles every day and now can't do this I feel housebound"
- "I was a postwoman and now I'm frightened of leaving the house"
- "This appointment has changed my life"
- "Liked being able to talk about symptoms
- "I have never talked to anyone about this before"
- "I usually come in and get tablets it's great to talk"
- "You struggle on your own and live with pain, you don't bother mentioning it to the doctor as you think there is no point"

### Patients with MSK only who attended for a second time during phase 2 at Glenpark or Niddrie (they had attended for their first time in phase 1)

Due to the timeframe of the programme it was not possible to record many second CSP appointments for people with MSK. The limited data is captured below and is inconclusive in terms of making recommendations about the frequency of ongoing CSP cycles for people with MSK only.

Patient 1	OA worsening	
Time not captured	Planned x-ray	
	Discussed work conditions	
	Advised about stretches	
Patient 2	OA, OP	
20 min allocated –	Intermittent pains in hands	
13 min appointment	Given Ibugel prescription	
	Patient quote "answered all my questions last time"	
	HCP reflection "worthwhile but possibly did not need to come this year"	
Patient 3	Main concerns - pain, weight, fatigue	
30 min allocated –	Prefers to avoid medications	
29 min appointment	Difficulty mobilising	
	Check bloods re fatigue, ARUK leaflets, topical gel, referral to social	
	service for other issues, weight reduction	
	HCP refection "yes, worthwhile consultation"	
Patient 4	Decline in health and pain	
20 min allocated –	Upcoming surgery	
46 min appointment	Keeping independent - discussed post op	
	Goals to manage pain and activity, pacing themselves	
	Mindfulness teaching worthwhile	
	HCP quote "this is inspirational for me"	
Patient 5	Chest infection	
20 min allocated –	Patient quote "Having OT last time has been life changing"	
19 min appointment	Happy with progress	
	Worthwhile – "yes"	

# Appendix I - Report on the qualitative interviews with staff and patients concerning their experiences of care and support planning for people with musculoskeletal conditions

#### **Angela Coulter**

#### Introduction

As part of the second phase of the feasibility study to introduce care and support planning (CSP) for people with musculoskeletal conditions (CSP-MSK), the Year of Care team and Versus Arthritis were keen to learn more about the experiences of those directly involved in its implementation. As an independent researcher involved in helping to evaluate the first phase of the study, I was asked to conduct in-depth interviews with staff and patients during phase 2. This report describes insights gained from these interviews. As well as contributing to the final report of the feasibility study, I hope it will be useful when planning a more formal evaluation of the programme.

#### Feasibility study, phase 2

Phase 2 involved five general practices, all of which had prior experience of implementing CSP for patients with 'QOF' conditions (e.g. cardiovascular disease, diabetes, respiratory conditions<sup>11</sup>). Two of the practices had been involved in the phase 1 feasibility study of CSP-MSK, while the other three had not. Four practices were located in Gateshead and one in Edinburgh.

The aim of the qualitative interviews was to explore views on the following topics:

- How easy/difficult has it been to introduce CSP-MSK into general practice?
- Did staff feel sufficiently well-prepared to deliver CSP-MSK?
- Did staff think patients had benefited from CSP-MSK?
- Did patients think they themselves had benefited from CSP-MSK?
- Is there a case for continuing to offer CSP-MSK?

In February 2019 I visited each of the five practices and carried out face-to-face interviews with nine practice staff – four GPs and five nurses, all of whom were directly involved in delivering CSP-MSK. Patient interviews were conducted over the phone. Practice staff approached patients who had experienced the CSP-MSK process to obtain their agreement to be contacted. I was given the names and phone numbers of 21 patients but was unable to contact two of them despite several attempts. Telephone interviews were therefore completed with 19 patients.

#### Implementation and variations

#### Adapting the model

The Year of Care Partnerships' standard approach for implementing CSP with one or more QOF conditions involves searching chronic disease registers to identify eligible patients, inviting them in

<sup>&</sup>lt;sup>11</sup> The Quality and Outcomes Framework (QOF), part of the GP contract for England, offers financial incentives for performance against a set of pre-determined indicators in relation to certain chronic conditions and preventive measures.

for an initial information-gathering appointment during which diagnostic and monitoring tests are carried out (if relevant) and reported to the patient. The principles of CSP are explained to the patient at this meeting and they are encouraged to think about their health priorities and support needs in preparation for a CSP meeting with a doctor or nurse about two weeks later. Those who do not need tests are sent a letter and accompanying information explaining the process and encouraging them to make an appointment for CSP.

Since care for MSK conditions does not constitute part of QOF, the general practices involved in the feasibility study had to begin by creating disease registers for these conditions. This involved ensuring that coding systems were regularised - no mean task, since numerous Read codes are available and these were not always used consistently. Several of the MSK conditions included in the project do not require regular blood tests, for example osteoarthritis, fibromyalgia and back pain, so an information gathering meeting was considered unnecessary for these patients. Instead, specially designed preparation prompts and information leaflets were developed.

#### Recommended approach

The recommended steps for implementing CSP-MSK, developed during phase 1, included, among other things, establishing training workshops for staff, cleaning practice registers to enable identification of MSK conditions, running electronic searches of practice records, establishing responsibility for administrative and clinical procedures, checking lists of eligible patients and removing those for whom CSP was not deemed appropriate (for example, those receiving palliative care or those with dementia), planning clinic times, organising staff rotas, and sending invitations to patients for annual appointments in their birthday month. Standard templates, letters, leaflets, prompt sheets and questionnaires were provided to guide the process. Staff were asked to complete reflection sheets after CSP conversations summarising the main points of discussion and agreed actions. The feasibility study also involved various additional data collection requirements to monitor activity and outcomes.

Those patients with multiple long-term conditions, including 'QOF' conditions plus any MSK condition, together with those diagnosed with gout, RA and other inflammatory conditions, all of whom require monitoring checks – the 'multi-morbidity' group - were invited to attend an initial information gathering appointment with a nurse or health care assistant, followed by a CSP consultation about two to three weeks later. Those with osteoarthritis, fibromyalgia, back pain, osteoporosis and fragility fractures and other conditions not requiring regular monitoring tests – the 'MSK only' group – were sent an invitation to a CSP consultation in the post, together with a package of information to prepare them for the consultation.

While all five practices broadly followed these guidelines, they were adapted to fit local circumstances and preferences, resulting in some significant variations.

#### Patient invitations

Some practices issued invitations to all patients with a MSK diagnosis whether or not they were on medication, while at least one practice restricted invitations to those on medication. One practice, whose usual call-recall system was outsourced to an external company, issued face-to-face invitations to patients with MSK conditions when they came in for other reviews, either for QOF

tests or for medication reviews. Another practice invited all patients with two or more long-term conditions, including MSK, for an annual review, together with opportunistic invitations when appropriate.

#### Organisation of appointments

In some practices all CSP consultations were provided by nurses, while in others GPs were also involved, often focusing on medication reviews or on patients with more complex problems. Two practices established special MSK clinics led by GPs with a special interest, while others adopted a holistic approach, with no special focus on MSK unless patients indicated they wanted to talk about this. Some practices allocated a fixed time, usually 20-30 minutes, for all CSP appointments, while others adopted a more flexible approach, with pre-consultation triage enabling allocation of extra time for those with complex problems. At least one of the practices took great care to check the records of MSK-only patients, going through about 60 records each month to check the eligibility of those identified by the electronic search.

"It takes one to two hours to do, but it's worthwhile. The coding seems to be getting more accurate now, so it takes a bit less time than it did. But it's OK because I feel it's clinically worthwhile. It never feels like a chore." **GP** 

#### Uptake

The likelihood that patients would accept the invitation and turn up for a CSP appointment seemed to vary according to whether they had prior experience of CSP, whether they were used to attending regular medication reviews, and whether their appointment was conducted by a doctor or a nurse. Uptake was relatively high where CSP-MSK was linked to reviews of QOF conditions or medication reviews, but it tended to be lower among MSK-only patients.

The GPs who ran special clinics for MSK patients had no trouble filling their appointment lists, but some of the nurses reported that only about 20% of MSK-only patients who were invited actually attended. While some staff found this disappointing, others felt that those who really needed it did accept the CSP invitations, attending the appointment and gaining benefit from it. Some staff felt it was reasonable to assume that those who did not come were coping well and did not require medical help, while others worried that this 'opt-in' system meant that some of those who could really benefit might have slipped through the net.

#### Multi-morbidity vs. MSK-only

While some interviewees felt that MSK should be treated like any other long-term condition in a holistic approach to multi-morbidity management, others were concerned that MSK issues might be missed if this approach was adopted, fearing that discussions would be dominated by cardiovascular and respiratory issues that are often viewed as a priority by staff. Several interviewees felt that nurses doing more general CSP consultations might not have time to probe for MSK problems or might not feel sufficiently confident to do so.

#### Managing the process

#### Preparation materials

The Year of Care approach stresses the need to prepare patients for CSP. Information gathering appointments enable separation of clinical tests and monitoring from CSP conversations, allowing more time to explore issues of importance to patients. Test results (where relevant) are usually shared with the patient prior to the CSP appointment. Information gathering appointments also offer an opportunity to explain the CSP process to patients, encouraging them to reflect on their health priorities before attending the main appointment.

For those with MSK conditions not requiring prior tests, preparation consisted of sending out invitation letters, preparation prompts and, if desired, specially designed educational leaflets on MSK conditions that could be mailed out in advance or handed out during CSP discussions. Administrative staff were also trained to answer patients' questions about the process when they rang to make appointments.

All practices sent MSK patients invitation letters and preparation prompts inviting them to circle the issues they would like to talk about. There were two different letters, depending on whether the patient was invited in for an information gathering meeting or not, so administrators had to ensure that the right letter was sent to the right patient. Some practices found this difficult to implement.

"What was really tricky, oddly, because it's perhaps one of the most important parts of CSP - where somebody learns about their results and has an opportunity to think about them before they come – that's been really difficult to implement. Initially it was because management said "Gosh, we can't send out loads of letters. This is going to be frightfully expensive", and some nursing staff said, "Oh they won't understand a thing." So the idea was difficult and the process has been complicated. We keep on coming across hitches." Nurse practitioner

Preparation prompts made it clear to recipients that they could talk about a wide range of issues, not just medication or MSK problems. This aspect seems to have worked quite well as far as patients were concerned. Several remembered the yellow sheets on which they had circled the topics they wanted to discuss. One practice sent out a very detailed template with a long list of issues intended to form the basis of a care plan. This turned out to be cumbersome and time-consuming to manage, so this practice has now decided to adopt a much simpler electronic template.

#### **Educational leaflets**

The extent to which the educational leaflets were used was unclear. Some staff interviewees were not sure exactly what was being sent out by administrative staff or handed out during information-gathering meetings and only a few of the patients I interviewed remembered receiving a leaflet.

"Giving people information about joint problems prior to the second meeting hasn't been working well in this practice. The process isn't streamlined enough. Health care assistants couldn't lay their hands on the leaflets in a timely manner."

Nurse practitioner

Since the CSP philosophy stresses the importance of allowing patients to discuss what matters most to them, it is understandable that practices might not want to hand out educational leaflets prior to the discussion that might be seen as influencing its focus. On the other hand, keeping a stock of leaflets available, either on paper or on the computer and accessing them quickly during a consultation is not always straightforward.

#### Data-gathering

The feasibility study involved significant additions to practices' usual data collection systems which some managed without apparent difficulty, but others found quite burdensome. These data were required as part of the evaluation to monitor the impact of the project on activity and outcomes. At the outset of the project time and effort was devoted to training staff in the administrative and data gathering aspects, but this knowledge tended to get lost when staff moved on. Job changes, illnesses and maternity leave were disruptive, requiring clinical staff to step in to sort out problems. Some staff felt the paperwork was interfering with their clinical time.

"Paperwork was the biggest challenge. It impacted on the consultations because you were so aware of the need to tick boxes – lots of things to fill in – big piles. I was sitting here in the evening filling them in. I'm not negative at all about CSP, but it got to the point where I wasn't looking forward to them because of all the data collecting." **Nurse practitioner** 

One nurse reported that she had been able to set aside an afternoon a week to keep on top of the administrative work, including data gathering, and she felt the process was now fairly smoothly. Others admitted that they had simply ignored some of the data requirements, making it likely that their data monitoring reports were incomplete. They were apologetic about this because they understood the importance of evaluating the programme, but it is an indication of the pressure that many primary care staff feel themselves under – when time is short clinical work takes priority.

The feasibility study intended to test the use of two Patient Reported Outcome Questionnaires (PROMs) – the condition-specific MSK Health Questionnaire (MSK HQ) and the generic Long Term Conditions Questionnaire (LTCQ). The MSK-HQ was used as a discussion prompt in phase 1, but both questionnaires can also be used to screen for severity and as outcome measures. Some practices sent or gave copies of these paper-based questionnaires to patients in phase 2, but very few were returned completed.

There are a variety of possible reasons why this aspect of the feasibility study did not work well. Administrative difficulties and work pressures may have meant that the questionnaires weren't given to patients, or they were given out but patients were not sufficiently interested to return them or not prompted to do so, and perhaps their function was not properly explained to staff and patients. This is a pity because PROMs are the best means currently available to quantify the health impact of CSP.

#### IT systems

The electronic searches to identify patients with MSK diagnoses appear to have worked reasonably well. Some interviewees felt their practice's involvement in the project had helped to improve the quality of clinical coding.

Some of the administrative challenges mentioned above might have been more readily overcome if electronic record systems were designed to accommodate the requirements of CSP. Documents such as care plans usually have to be scanned into the computer and are not integrated into individual patients' records. In some cases staff were manually inputting free text reports of key points agreed during CSP discussions.

Making it easier for patients to book appointments, receive reminders, and access information, educational leaflets and care plans electronically could do much to reduce the administrative load on practices. Similarly, inputting responses to PROMs questionnaires, analysing these and aggregating the results would be much easier if they were in electronic form rather than paper-based, and available on an interactive patient portal. Perhaps the NHS App, currently being piloted and due to be rolled out across the country later in 2019, will solve some of these problems.

#### Staff training

Many of the staff involved in CSP-MSK had prior experience of Year of Care training and some had acquired several years' experience of applying these skills through their involvement in delivering CSP for other conditions. Special training in MSK issues was provided as part of the feasibility study. All those who attended these sessions found them useful. Illuminating talks given by a rheumatologist and a pain clinic nurse were highlighted as being particularly helpful, especially by nurses who said these sessions had boosted their confidence to deal with MSK problems.

"I now have a completely different idea of what's involved. For me it has been really beneficial and for the patients I can now present it in a way that's more helpful. Before, I didn't really know what I was offering them. The big thing for me was the realisation that it isn't about getting rid of pain but managing it. As a nurse you want your patients to be pain free, but I now understand that that's not an appropriate goal for chronic pain." **Nurse practitioner** 

A nurse practitioner who had enjoyed a workshop organised by Year of Care compared it favourably to another course she had attended run by a different organisation that was badly organised, patronising and rude about doctors, causing her to leave part way through!

Several interviewees indicated that nurses were quite often reluctant to get involved in CSP-MSK because they felt they didn't have relevant skills and lacked knowledge of pain medications.

"The biggest issue is nurses' confidence that they can make a difference to MSK problems. Teasing out the real issues can feel a bit overwhelming in a limited time. Knowing the phrases and questions to ask to enable people to talk about what's really bothering them, and drawing out what's difficult, for example steps, access, transport barriers, also confidence in dealing with particular conditions, e.g. fibromyalgia. I think training in analgesia would be helpful for all, including non-prescribers." **Nurse practitioner** 

Interviewees also stressed the importance of encouraging all members of a practice team to attend CSP training workshops, including practice managers and administrative staff, but staff turnover and recruitment difficulties often get in the way.

#### Impact of CSP-MSK

#### The invitation

Several patients said they had been surprised to receive the invitation to come and talk about their health, while others saw it as just another annual review similar to ones they had attended before. All those I interviewed said they were pleased they had attended the CSP appointment.

"I got a letter through the post with this form in asking questions and inviting me because I had COPD etcetera. So I thought oh, very nice. I'm happy with that so long as they don't ask me to have any more pills. You go to the doctors usually for a specific reason but there's often something else that you want to mention but you never get round to it. I just love the fact that this paper asked me how I was coping and more or less asked me what I was doing with my life. And I could understand that because I'm very active and intend to stay that way. And I just love the fact that everything I wanted to say was down on paper, so it was there to be brought out. I just thought it was fabulous!" **Person with MSK condition** 

While some said they didn't know what to expect, other patients were attending for the second time but still found it helpful and reassuring.

"I had another appointment and revisited all the things we had discussed before. When you're feeling unwell it's hard to stay focused. It made me realise that there are other people who are just like me. You tend to think that your pain is the worst. You come away from the meeting with reassurance." **Person with MSK condition** 

"It's like taking your car for an MOT and finding out things that are wrong that you can act on. And if there's anything underlying they would pick up on that and put you in the right direction." **Person with MSK condition** 

#### The conversation

Staff reported that the project had drawn in patients who had struggled for years with MSK problems, with major impact on their quality-of-life.

"I had to leave my previous job because of the pain. I was starting to get depressed, feeling like a nuisance at work, going to work crying. What good am I here if I can't do anything?" **Person with MSK condition** 

Most patients welcomed the opportunity to talk to a health professional about their joint pain. For some it was first time they felt their pain and joint problems had been taken seriously by a clinician.

"It was certainly helpful for me, if for no other reason than the fact that it made you feel as if you're important to somebody and you're not on your own. I know everybody's different but I'm a widow and I am on my own, and sometimes you just feel that — is anybody interested in this? It was good for me that the doctor did take time to ask how things are going." **Person with MSK condition** 

One patient described a past experience where they felt their concerns had been dismissed, leaving them feeling embarrassed about wasting the doctor's time.

"When I went with knee pain quite a few years ago, I was sent for an x-ray. I went back for the results and the doctor was very blasé. He just kind of said oh well, you've got some kind of degenerative changes. I was in and out and left feeling that I'd wasted their time. But actually I've got arthritis in my knees. I know it sounds stupid but I didn't realise that. It's really important to know so I can take good care of my joints." Person with MSK condition

In contrast, the CSP-MSK appointment provided legitimation of their concerns, ideas about how to cope with their health problems, and reassurance. Some interviewees spontaneously mentioned the more open, patient-centred style of conversation, which was quite different to what they had been used to.

"When you go down to see a GP you have to tell him what you think is wrong with you and they respond to that. But I found with this it was far more open. They would be asking you questions as to what was wrong and how you did this. It was much more open than the doctor answering just the questions that you gave them." **Person with MSK condition** 

The importance of having someone to talk to about their pain and being listened to was emphasised by many interviewees.

"For me it was certainly a good idea. I was feeling a little bit low at the time and just talking to her made me feel better. I have constant pain. I've never been without pain since last year, so it was nice to talk to someone about it." **Person with MSK condition** 

#### Self-management support

Staff interviewees indicated that supporting people to help themselves was a key element of CSP.

"A worthwhile consultation is when the patient leaves feeling empowered, that they have some control over their problems, that I've been able to help by signposting, enabling them to help themselves, rather than here's a prescription for some codeine." **Nurse practitioner** 

"Typically a good consultation is when the patient is open to the idea of self-management and agrees actions they can do. They formulate a need and you have a match for it. Then it's great. Other good consultations are when it becomes clear that they're not coping, often because of mental health issues, weight, drug use. They just need supportive, unrushed prompts to open up and then you can pick them up. You don't know what they want when they come in, but you're able to offer some kind of support." **GP** 

Staff reported that many patients tended to be fatalistic about joint problems, assuming that nothing can be done, apart from taking pain medications. The importance of building and sustaining muscle strength through appropriate exercise is widely misunderstood or ignored. Misperceptions about fragile bones give patients the mistaken impression that their condition will be made worse if they exercise. This makes inactivity more likely, leading to overweight and other health problems. These misunderstandings can sometimes be traced back to unhelpful language people have heard

from health professionals in the past, for example talking about 'crusty', 'creaky', or 'crumbling' bones.

"Many people think joint pain is inevitable and will only get worse. Many are told it's wear and tear when they're diagnosed, you're over 50 – quite normal. They think there's nothing much you can do. One of the best things about this project is when people come in assuming they'll get worse and end up in a wheelchair, but you give them information about stretching, weight loss advice, exercise, dance classes, and they go out feeling much better and more hopeful." **GP** 

All staff said they try to emphasise the importance of keeping active, but it isn't always possible to motivate patients to do so.

"Those who are proactive in following advice can make huge improvements, but a lot of people won't exercise or lose weight. It's up to them to decide what they want to do. Well over 50% do try to follow the advice at least in part – exercise, weight loss, how to use medication. A small proportion follow all the advice." **GP** 

Being overweight was a concern of many patients – several talked about their struggles to lose weight.

"I have to lose some weight [awaiting operations on both knees], but I'm going on holiday next week for a fortnight. She says just do sensible eating, not too much rich stuff, to keep away from the greasy stuff and that. I try my best to keep away from the fatty things. It's going to be difficult on holiday." Person with MSK condition

For some patients the CSP consultation gave them a better understanding of their condition leading to lifestyle changes.

"I haven't been doing the exercises because I'm not very good at exercising on my own, but I have actually joined a Pilates class as a result of the consultation which I started last night. I do a lot of walking but the particular muscle groups that the doctor said I had to strengthen — I don't think I'm really hitting that muscle group just by walking." **Person with MSK condition** 

"I've been doing exercises. They helped tremendously. I still exercise when in the bath — water helps with pain. I do like to go for walks. It hurts but I refuse to give up." **Person with MSK condition** 

Sometimes a discussion with a doctor or a nurse is sufficient to prompt a change.

"She suggested going to the baths and just walking, which I've been doing. It has helped. I look forward to my appointments with her actually." **Person with MSK condition** 

"One patient wanted to lose 5 kilos. "I've done it!" she said. What made the difference? "We agreed it and I didn't want to let you down."" **GP** 

"I intended to make sure that I continued with the attitude that you've got a life, live it, and don't spend it in the chair. I don't really know what it was – it was a

whole different experience. It was right up my alley because it made me think." **Person with MSK condition** 

Interviewees emphasised the importance of encouragement and support, but also stressed the need not to expect dramatic changes and never to make people feel guilty if they are unable to reach their goals. Small steps can represent great achievements.

"I've seen some positive changes, mood improvements, reversal of trend, starting to do a little bit of walking maybe once a month. One patient came in to say "Doctor I signed up for the triathlon! Go on a bike (no distance involved), walk for five miles in January, and go swimming twice." Fantastic! She failed on the walking but did everything else." **GP** 

#### **Medications**

The doctors involved in CSP-MSK usually devoted part of the time to reviewing patients' medications. Quite often this revealed opportunities for medicines optimisation and deprescribing. It was common to see patients who had been prescribed inappropriate drugs or very high doses that were causing more harm than good.

"Many patients assume that doctors aren't interested and nothing can be done about their pain anyway. Some may just have to cope with pain. It's easier to cope if you have good support from primary care. Accuracy of diagnosis is important, appropriate painkillers, advice on painkillers, advice on when not to use them, upper limits, understanding that might have to cope with a degree of pain, getting people off medication. Some are on significant doses because people have been trying to help but end up giving too much morphine. That's been an important part of the clinics." **GP** 

At the outset of the project some staff had been concerned that inviting people with MSK problems in for a discussion would lead to an increased use of resources, including prescriptions.

"Our prescribing lead was initially quite anxious that the project would lead to increased use of painkillers, but that hasn't happened. We've actually done quite a lot of deprescribing. Many patients are pleased to stop taking painkillers." **GP** 

Patients' fears about dependency on painkillers can sometimes lead to irrational patterns of use, so CSP-MSK meetings often focused on how best to self-medicate.

"I was told that paracetamol is probably the best sort of thing I can take. I was just taking it, for example, at the gym. I would take just a couple of tablets and that would be it. But they said you should keep a constant level of paracetamol in your system for a week or so. So I was prescribed paracetamol which I would take four times a day instead of just taking it when I thought I would need it." **Person with MSK condition** 

#### Referrals to specialists

Sometimes the opportunity to review a patient's health issues leads to a specialist referral. However, for the most part staff interviewees did not think the project had led to an increase in their referral

rates. Indeed, some felt it might have reduced them because they were now better equipped to deal with the problems in primary care.

Gateshead practices can access the Tyneside Integrated Musculoskeletal Service (TINS), a single point of access to specialist teams, including physiotherapy, rheumatology and orthopaedics. It also offers self-referral via a website. Launched in October 2018, its original intention was to make self-management support a key focus, but interviewees felt it was struggling to meet a heavy demand and waiting times were long and getting longer. The Edinburgh practice also experienced long waiting times for referrals to orthopaedics and rheumatology.

The local pain clinic in Gateshead was reported to be very supportive of the project. There is also well-organised multi-disciplinary specialist care available for patients with rheumatoid arthritis in both Gateshead and Edinburgh, but general practices continue to deal with the majority of MSK issues. Some MSK patients benefited from home visits by occupational therapists, who were able to respond reasonably quickly to GP referrals. Referrals to podiatrists were also used and found helpful. Other services, such as weight loss clinics or exercise programmes are no longer available on the NHS locally, forcing practices to rely on services run by commercial organisations or charities.

#### Social prescribing

Social prescribing, often referred to as 'more than medicine', is a key feature of CSP, and many patients appear to have benefited from it. All the practices involved in the project had access to a community link worker who could help connect patients to local community-based services, such as weight loss and exercise programmes, mindfulness, bereavement counselling, hobbies or social activities.

"When a patient says "I can't cope with anything doctor, because you haven't killed my pain yet – everything is too sore", you're in a stalemate situation. Then we refer them to the community link worker who works on this, asking "What will make a difference to you?". His job is to help with pain management, help to lead a fulfilling life, coping strategies, taking away some of the anxieties." **GP** 

Both Edinburgh and Gateshead are relatively well resourced when it comes to community facilities, but recent financial cuts have led to the withdrawal of certain subsidies so there is often a fee to pay. Accessibility and public transport costs can also be a barrier to making use of these. Staff explained that eligibility criteria for financial support to attend these activities are constantly changing, making it hard to know what's available and for whom. Link workers can provide practical support, including accompanying patients to relevant facilities when necessary.

#### Is it worthwhile?

#### Benefits

All the primary care staff I interviewed were convinced of the value of CSP-MSK for virtually all the patients they saw. This view was reinforced by positive feedback they had received from patients.

"Patients usually give good feedback – they often say it's been really helpful. They really look forward to it mostly. One lady said "I look forward to getting my yellow form through the post more than a Christmas card!" It's being listened to more than anything – an opportunity to ask whatever they want to, not just coming in to get results and be told what to do. It's their agenda. We'll listen to them and work with them. It's their plan." **Nurse practitioner** 

"For patients the benefit is being able to talk about something they haven't been able to talk about before, being listened to. Care plans are helpful, also dealing with mood problems. Making a little bit of an impact on activity is good. I've seen these benefits in some patients. I've always felt that there's much more that can be done than just painkillers." **GP** 

"Extending CSP to MSK makes perfect sense. Won't go back." Nurse practitioner

The opportunity to surface issues that might otherwise be overlooked, and to oversee and rationalise treatment plans that no one has time to review in a standard ten-minute consultation was seen as very beneficial.

"I've had most successes with osteoporosis and gout from the point of view of managing their condition better. I've noticed that we don't manage osteoporosis very well. Gout and osteoporosis should have regular bone scans or blood monitoring to check control. Pain is a dominant factor for many patients. For example patients called in for a diabetes review will often talk about pain first rather than their diabetes." **Nurse practitioner** 

"It's nice to have 20-25 minutes just to focus on one thing. You can't do everything in a 10 minutes slot. It's really nice and patients appreciate it. Listening, taking time to discuss – it's massively appreciated. Patients are used to their joint problems being ignored. There's no doubt it's been of benefit." **GP** 

In practices that have been doing CSP for some years, staff reported that many patients now look forward to their annual review and are pleased to be called back in, often raising new health issues they want to discuss.

"Some people come back the following year just to share what they've been doing and how it's improved their life. A lot are so used to it now. For example, a lady who has COPD came in to say everything's fine – action plan, inhalers, rescue pack, BUT..... and then she gave a long list of other things that were nothing to do with COPD. She knew that was what the appointment was for. That's common – they know what the reviews are for now." Nurse practitioner

#### Challenges

Despite their confidence that CSP-MSK was benefiting their patients and leading to quality-of-life improvements, some interviewees intimated that their colleagues were less convinced of its value to the practice.

"I'm not sure if others in the practice are convinced of the value of CSP." GP

Some GP interviewees said their partners and other colleagues shared a general feeling that arthritis and other MSK problems had not been getting the level of attention that was needed, but they were unsure about its sustainability when faced with high levels of demand and limited resources, exacerbated by recruitment difficulties. Every 20 – 30 minute consultation devoted to CSP-MSK, plus

the extra time required for administration, record-keeping and data gathering, reduces the time available for standard appointments. This might balance out if it can be shown that investment in CSP leads to greater efficiencies down the line, but not everyone was convinced that it would. And it is hard to take on new work if you can't find the staff to do it.

"In the old days we would get a locum or ask for more funds, but we can't find the doctors now. It's really difficult to set up a new service without working out how we're going to do it, due to lack of capacity. It was much easier ten years ago. We have to take it out of the pool of appointments, so there's a knock on effect on the other patients. I currently do only two joint clinics a month, but that takes out 15-16 appointments. In the long run providing the extra clinic will be difficult because of the extra burden on staff. It's not just a case of saying here's a bunch of money, go and run a clinic. Now there are no docs to recruit." **GP** 

While some practices struggled to recruit doctors, others found it more difficult to recruit nurses with the right skills. Many of those currently involved in CSP-MSK are highly trained advanced nurse practitioners, but even some of them admitted that they found it challenging at times.

"Dealing with people with lots of long-term conditions and complex pain problems can be difficult. I sometimes feel a bit out of my depth, especially when we also have to do frailty assessments and reviews. It's easy to get side-tracked when there are lots of different problems to address. I sometimes worry about things I haven't done after the patient has left. It's difficult to ask them to come back. I sometimes feel a bit overwhelmed." Nurse practitioner

Most practices had established supportive arrangements for the nurses to discuss complex cases with GPs or other members of the team and for internal referral where necessary, but it is not hard to understand why some nurses might not want to take on the additional responsibility of CSP. Training, supervision and support are key to helping them cope.

#### Will it continue?

I asked interviewees whether they intended to continue with CSP-MSK once the feasibility study had ended, and if so whether they would want to modify it in any way. All responded positively saying they were determined to continue if they could, but there were varying ideas on which patients could benefit most.

Some were particularly keen to continue inviting MSK-only patients who they felt got a great deal of benefit from it, while others were not sure they would have the capacity to continue calling in these people. There were mixed views on the feasibility of continuing to focus on patients with osteoarthritis. All agreed that catching these problems early is a good idea, but some advocated a more opportunistic approach for those patients they felt would benefit most, while others thought this might be complicated for administrative staff to manage.

If forced to choose, some felt that patients with rheumatoid arthritis already received quite good systematic care from the hospital so may have less need for CSP, although it was acknowledged that these patients did appreciate the chance to talk with primary care staff. Some interviewees felt the same applied to patients with gout, while others disagreed on the grounds that this group of patients needed the level of systematic care that CSP can facilitate.

Another option advocated by some was to rely on the prompt sheets sent out when patients were invited in to discuss QOF conditions. If these made it clear that pain and joint problems were legitimate topics to raise, that might be sufficient to identify those for whom MSK problems were a priority. It this approach was adopted, it would still be important to ensure that the nurses received training in dealing with MSK problems.

One GP, from a practice where all partners are involved in CSP, argued that it is relevant to any long-term condition and should be integrated into the everyday business of the practice, recruiting patients opportunistically in addition to the more proactive and systematic approach piloted in the MSK feasibility study.

"You could catch a patient when you think there's an opportunity there, when they say doctor I'd like to change something. You could say, why don't you go away and think about it and book yourself in for a conversation in a couple of weeks' time. Or you could break the conversation into different consultations—identify a goal, then come back in a couple of weeks' time to see what we can do to help you achieve those goals. Or come back with the reading you've been given and with your ideas on what you can do. We'll definitely carry on with it. All partners are committed and signed up to it. It's relevant for all major health problems that affect many people's lives." **GP** 

#### **Conclusion from interviews**

The general impression gained from these interviews was of strong commitment to the CSP process, and firm belief in its benefit to MSK patients, albeit tempered by a level of concern about feasibility, given the pressures facing general practice at the moment.

In the current climate, establishing the cost-effectiveness of the programme will be crucial. A patient I interviewed, who had no doubt about its value, put her finger on the issue that now needs to be resolved.

"In terms of a cost-benefit analysis – in terms of the ten minutes of the doctor's time versus me needing knee surgery a lot sooner than I would, I think it was definitely a good investment because hopefully I'll be able to keep any problems at bay for a few more years." **Person with MSK condition** 

Future research should focus on addressing this important issue.

25/03/19