



REPORT ON PHASE ONE OF
BRINGING MSK CONDITIONS
IN FROM THE CARE
PLANNING COLD - A
FEASIBILITY STUDY
IDENTIFYING ISSUES FOR
PHASE 2

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 MSK conditions either alone or together with other long-term conditions (LTCs). The current project '*Bringing MSK conditions in from the care planning fold - a feasibility study*' is a response to this and was commissioned to work out how this could be achieved in practice.

This report comes at the end of phase 1 of a two phase approach designed to tease out the issues of practical delivery and develop the tools and MSK specific resources, so these can be tested and refined as part of a multimorbidity approach to CSP in phase 2.

We are well on the way to achieving this having developed the core tools and resources to test for transferability and confirmed that CSP has the same positive benefits for those living with MSK as has been reported for other conditions. It has also demonstrated there is much unmet need. In phase 2 we will describe this in greater detail, examine who can benefit most and how to ensure that MSK conditions get the attention they deserve as part of a multimorbidity approach to CSP. The final report will contain tested resources and recommendations for implementation and training.

This report is in three parts which may be of interest to different readers.

Part A describes the background and key learning from phase 1 of the project. **The executive summary** includes the main messages, implications and plans for phase 2 and will be of interest to ARUK as the project funders.

Part B includes the background resources, and quantitative and qualitative data collected in phase 1 linked to each chapter in part 1. This will be of interest to those involved in implementation during phase 2.

Part C includes the reports of the 3 visits to project practices made by Angela Coulter who worked alongside the project team to evaluate the activities.

Signed: Core CSP MSK Project Team

Contents

| | |
|---|----|
| Foreword..... | 2 |
| Executive summary: phase 1 summary and phase 2 proposals | 4 |
| Part A – The Findings | 8 |
| Chapter 1: project brief background and approach to evaluation | 8 |
| Chapter 2: how we went about it | 11 |
| Chapter 3: practice register and recalls for phase 1 | 13 |
| Chapter 4: inviting people into the care and support planning process - MSK..... | 17 |
| Chapter 5: preparation for CSP-MSK | 20 |
| Chapter 6: using the MSK-HQ and LTC-Q..... | 22 |
| Chapter 7: CSP in MSK – the conversation | 26 |
| Chapter 8: training issues..... | 30 |
| Chapter 9: links with wider community - more than medicine and specialist services | 32 |
| Chapter 10: evaluation and impact to date | 34 |
| Acknowledgements..... | 37 |
| Part B – The Data | 38 |
| Data for Chapter 1: project brief and background and approach to evaluation | 39 |
| Data for Chapter 2: how we went about it | 41 |
| Data for Chapter 3: practice register and recalls for phase 1..... | 45 |
| Data for Chapter 4: inviting people into the care and support planning process - MSK..... | 47 |
| Data for Chapter 5: preparation for CSP-MSK | 50 |
| Data for Chapter 6: using the MSK-HQ and LTC-Q..... | 51 |
| Data for Chapter 7: CSP in MSK – the conversation | 52 |
| Data for Chapter 9: links with wider community - more than medicine and specialist services | 56 |
| Data for Chapter 10: evaluation and impact to date..... | 58 |
| Part C: Angela Coulter’s practice visit reports | 61 |

Glossary

| | |
|---------------------|---------------------------------|
| BH: Becky Haines | RA: Rheumatoid Arthritis |
| AK: Amelia Kerr | OA: Osteoarthritis |
| RB: Roland Baumann | CSP: Care and support planning |
| SL: Stuart Logan | CSP-MSK: This project |
| AC: Angela Coulter | YOCP: Year of Care Partnerships |
| LT: Lesley Thompson | HCA: Health Care Assistant |
| LB: Laura Boothman | |

Executive summary: phase 1 summary and phase 2 proposals

In phase 1 of the project Year of Care Partnerships (YOCP) worked intensively with three general practices serving diverse communities to identify the key issues involved in establishing care and support planning (CSP) as part of routine care for people living with MSK conditions as outlined in the ARUK Document *'Care Planning and Musculoskeletal health'*. Phase 2 will include a further two practices to test the transferability of the tools and resources developed; and work in depth with all 5 practices on the remaining issues involved in introducing CSP for MSK conditions as part of a practice wide approach to multimorbidity.

Headline learning from phase 1

- The core components of CSP (using the YOC 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).
- Just as those with other LTCs have previously reported, 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.

"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 at end of conversation**

"I've never talked to anyone about this" **Person during conversation**

- CSP enables previously undisclosed topics related to symptoms, daily living and overall function in MSK conditions to be raised 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" **BH**

- It is not yet clear if some people benefit more than others and if so how to identify them. Patient records lack sufficient information on disease 'activity', chronicity, severity and the functional impact of MSK conditions. Inviting people to identify their own need for CSP may be important.
- Between a third and half of people living with MSK conditions have other long-term conditions (LTCs) making a multimorbidity approach¹ to CSP essential. Between 10 and 20% have more than one MSK condition.
- Of the three ARUK groups, people living with some inflammatory and fragility conditions are already involved in systematic QoF resourced reviews. Those with musculoskeletal pain syndromes currently have little systematic care although codes for these groups are 3- 5 times more frequently recorded.
- The best way to ensure that MSK conditions get the attention they merit *within CSP conversations* (by using prompts / staff training etc.) is not yet established.

¹ A multimorbidity approach implies that all an individual's conditions/ issues are brought together in a single CSP recall process and conversation. Based on the ethos of *'the person not the condition'* this includes those who may live with only one condition.

- The centrality of pain and the need for a greater systematic, holistic and skilful approach to prevention and management within consultations, linked with better community support, is emerging.
- The purpose and practicality of using the MSK-HQ patient-reported outcome measure (PROM) within CSP has begun to be explored and the potential and issues associated with the use of the LTCQ PROM for phase 2 have been described.
- The benefits of supportive activities in the community and their haphazard availability and long-term insecurity have been noted.
- Once introduced, CSP in MSK is as rewarding to staff as in other conditions, though some find it challenging and identify further training needs.

“CSP creates happier teams” RB

Practical issues

- We have established Read codes and a search strategy to identify the three core groups of conditions outlined by ARUK. Indicative numbers are available.
- Identification from practice records of people living with MSK conditions who might benefit from systematic CSP, has been time consuming, because most of these conditions are not included in usual QoF recall systems. We have now developed a set of instructions for new sites to enable this to be carried out more easily.
- An 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, together with emerging findings from the conversations is beginning to identify those who can benefit from CSP but needs further development.
- We have developed the tools and resources for preparation within the CSP process tailored to MSK conditions but their use within multimorbidity consultations needs to be tested.
- The extent of unmet need for information and practical support in the musculoskeletal pain group, which has not previously been part of systematic review within QOF, is such that the first CSP cycle might be considerably more time consuming than subsequent cycles. The need / frequency of follow up is also not yet established.
- While it is likely that a significant number of people with MSK conditions can be incorporated efficiently within a multimorbidity approach to CSP, the overall scale of any additional practice support for this previously unresourced group still needs to be identified. Estimates based on phase 1 projections are now available as a starting point for phase 2.

Draft proposal for phase 2

In phase 2 we will work with phase 1 practices and two others to complete the overall project aims. The focus will be in-depth learning on the inclusion of MSK conditions as part of multimorbidity. The 12-month period will be divided up to gain maximum learning with minimum disruption to the practice. We will ask

- can the codes and search strategies developed in phase 1 be used to speed up the introduction of CSP into new practices? Are improvements possible?
- What is the best way to identify and record those who might benefit from CSP?
- What is the best way to incorporate MSK conditions into a whole practice approach to multimorbidity as routine care? How can the invitation and preparation tools used and developed in phase 1 best be used?

- What are the training needs (and specification for a training programme) for staff to ensure that MSK is properly addressed within CSP conversations, including approaches to pain?
- What are the practical issues and benefits of using the MSK-HQ (as prompt and PROM) and the LTCQ (as PROM) within CSP for MSK conditions as part of a multimorbidity approach?
- What is the perceived impact on patients, clinical staff and practice organisation of introducing CSP?
- What is the impact on resource use within the practice of introducing CSP?
- What community resources are needed/used?

Phase 2 draft project plan (below)

The core components of the phase 2 project include

- twelve months follow up of those patients seen in Glenpark and Niddrie during phase 1, including a repeat of the PROMS used in Glenpark (MSK-HQ: June to August and LTC-Q: Sept to January).
- Set up period using codes and searches identified in phase 1.
- CSP carried out as part of single condition and multi-condition recall and review over 9 months with post consultation reflection sheets completed.
- Intensive documentation of patients seen in a three-month period with follow up 6 months later.
- An initial training programme for clinical staff across all five practices, written recording of issues identified in consultations and use of a video consultation analysis tool for self-reflection will lead to the development of recommendations/specification for a holistic CSP MSK training programme.
- Analysis of conversations with and without the use of the MSK-HQ will test the usefulness of the questionnaire in preparation.
- Use of the MSK-HQ as a PROM at 6 and 12 months in different cohorts.
- The re-administration of the LTC-Q at 12 months for the 2017 Glenpark cohort with the potential collection of a larger sample in 2018 as baseline for potential future study.
- Weekly recording of resource used in CSP, and other practice resource use by 'tagged intensive cohort'.
- Interviews with patients and practice staff at key points.

Key reporting tools are under development – January 2018

Draft phase 2 plan (following January kick-off event)

| Phase 2: Glenpark and Niddrie | | | | | | | | | | | |
|-------------------------------|---|---|---|---|---|---|-------------------------------|---|---|---|---|
| F | M | A | M | J | J | A | S | O | N | D | J |
| | | | | Glenpark/Niddrie phase 1 patients having second CSP process with completion of consultation reflection sheets | | | | | | | |
| | | | | | | | Glenpark re- administers LTCQ | | | | |

| Phase 2: All practices | | | | | | | | | | | |
|---|---------------------------------|--|---|--|---|---|---|---|--|---|---|
| F | M | A | M | J | J | A | S | O | N | D | J |
| • Clean Register • Admin set up • Agree new code for 'CSP- MSK' | | | | | | | | | | | |
| | Training for all involved staff | | | | | | | | | | |
| | | Practices start CSP for whole MSK population each month as part of multimorbidity or separate clinic (if MSK only condition); using specific prompts / information sharing | | | | | | | | | |
| | | Completion of consultation reflection sheets | | | | | | | | | |
| | | | | *Intensive 2-month period documenting patients and CSP | | Follow up of non-responders | | | 6-month impact and outcomes measures on intensively documented group | | |
| Seek electronic entry of MSK -HQ and new formats for results | | | Use MSK-HQ in addition to usual prompts | | | | | | Re-administer MSK-HQ to intensive group as PROM | | |
| | | Potential use of VEO* in sample consultations | | | | | | | | | |
| | | | | | | | | | Training needs reassessment and criteria developed | | |
| | | | | | | Possible use of LTCQ as PROM in multimorbidity clinics, replacing MSK-HQ as baseline for future | | | | | |
| | | Use of practice resources recorded | | | | | | | | | |
| | | Possibly test opportunistic identification and coding within practice | | | | | | | | | |
| | | Interviews with patients and staff – discuss timing with AC | | | | | | | | | |

*Exact months when this starts to be discussed

Part A – The Findings

Chapter 1: project brief background and approach to evaluation

The project was designed to

- develop and test the practical requirements to embed collaborative care and support planning (CSP) as normal care within general practice for people living with single MSK conditions or who have MSK conditions as part of multimorbidity.
- Demonstrate the links with specialist care and activities in a supportive community.

This project is funded by, and directly supports the strategic focus of Arthritis Research UK (ARUK) for 2015-2020 to improve quality of life for people with arthritis so they can say *“I am in control, independent and recognised”*.

The aim is to develop specific practical learning in support of the recommendations of the 2013 ARUK Report *‘Care Planning and Musculoskeletal Health’* (Part B). These detail the responsibilities of NHSE, local commissioners, professional bodies and the Health and Social Care Information Centre (HSCIC) to ensure that systems are in place, staff are appropriately trained, and tools are available for monitoring the uptake and impact of CSP.

The project is entitled *‘Bringing MSK conditions in from the care planning cold - a feasibility study’* and is not a traditional study of impact. Instead it is designed to develop a reproducible approach to CSP for people living with MSK conditions.

The aspiration is an improved and more relevant experience of care, improved self-management and wellbeing and to contribute to the prevention of deterioration, further complications and more appropriate use of specialist services for people with MSK conditions.

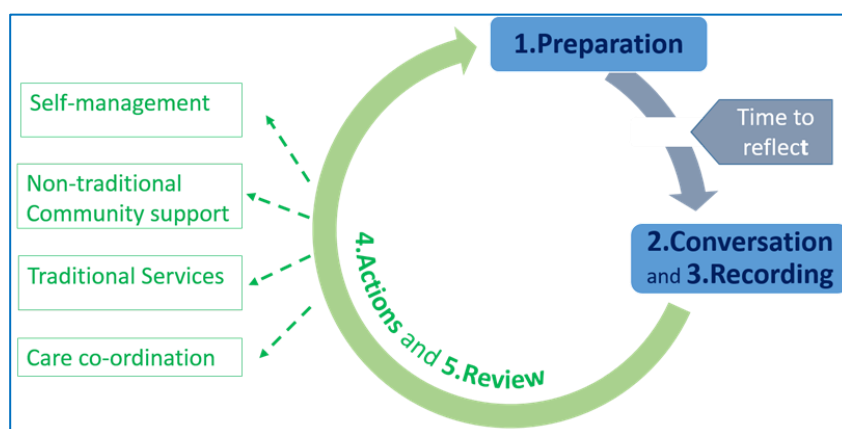
Care and support planning

CSP is about enabling better conversations between people living with LTCs and health care practitioners that are focussed on what matters to the individual, so that support and services can be tailored to each person. CSP includes 5 components (preparation, conversation, recording, actions and review) which all need to be in place if it is to be effective. This requires simultaneous changes to attitudes, skills and general practice infrastructure.

The care and support planning cycle

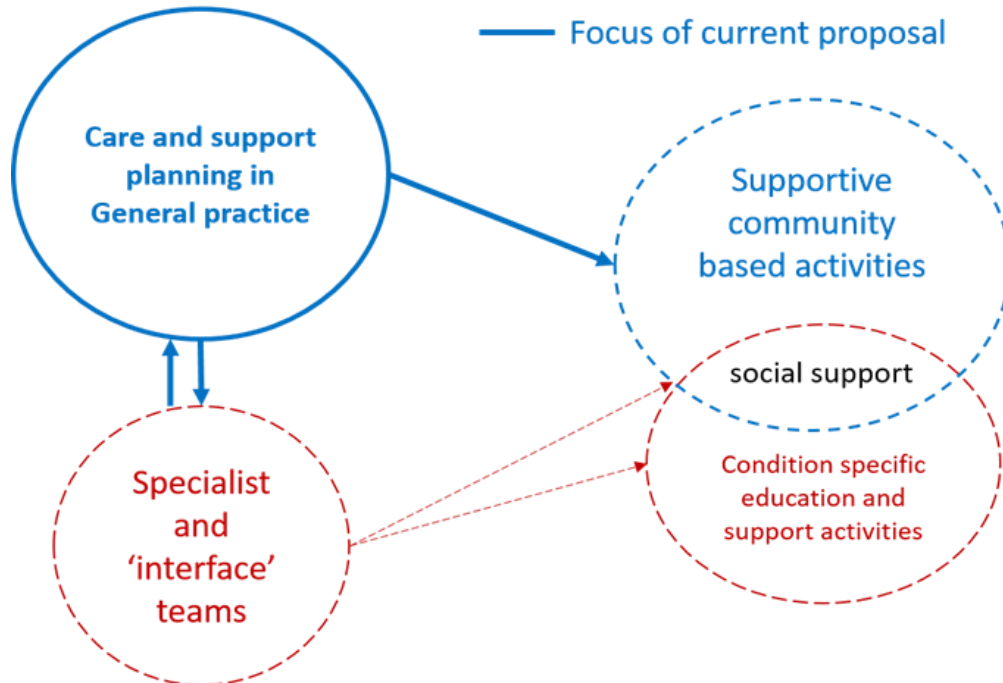
CSP differs from traditional care in focusing on the components of a ‘better conversation’, and actively preparing the person to be an equal partner in this. This includes sending reflective prompts, and sharing assessments and test results if

appropriate, ahead of the conversation with the healthcare professional to help them prepare for this. Practice systems are redesigned, tailoring the components to the specific conditions and circumstances of the individual.



This includes sending reflective prompts to help them prepare for the conversation with the healthcare professional, and sharing assessments and test results if appropriate ahead of this. Practice systems are redesigned, tailoring the components to the specific conditions and circumstances of the individual.

CSP is one component of community wide care and support for people living with MSK conditions. The diagram below demonstrates the focus of this project is on CSP within general practice and relationships with system wide MSK pathways.



Project phases

Phase 1: development (Jan - Oct 2017)

Three practices with different demographics and local organisation, already experienced in CSP for other LTCs, were chosen. The practice teams worked with the Year of Care project team to identify people living with MSK conditions and develop the processes and resources to enable them to be included in CSP.

Phase 2: spread and embedding (Jan 2018 - Jan 2019)

During phase 2 we will test transferability to two new practices and work in depth with all 5 practices to establish who can benefit from CSP and how this can be established as routine within a multimorbidity approach. Details of how we will do this are described in Chapter 12.

Approach to evaluation

AC, a co-applicant and member of the project management team, is leading the evaluation. This has three components in phase 1 developed from the overall project aims.

1. How successful have practices been in embedding effective CSP as normal care for those living with MSK conditions and is this affected by co- or multimorbidity?
2. What are the differences, if any, that relate to CSP in MSK conditions and how are practices tackling these?
3. How can patient reported measures be collected and used in the context of routine CSP for people living with MSK conditions as recommended by ARUK report? The project will

specifically test the feasibility of using two recently developed PROMS, one specifically for people living with MSK conditions (MSQ-HQ) and the other for those with single or multiple long-term conditions (LTCQ).

AC has worked alongside the practices and the core team to refine the evaluation questions and select the evaluation tools and processes for phase 2.

Chapter 2: how we went about it

Core operational project team and establishing a group of critical friends

We identified the core operational team during the bid process, please see details in Part B.

We also established a group of critical friends for two reasons. The first was to ensure that the design process was informed by people with practical experience both as providers and service users with a strong commitment to person centred approaches. The second was to ensure credibility with the wider MSK community.

Identifying the phase 1 practices

The opportunity to take part was advertised within the Year of Care (YOC) community of practice via a national event in June 2016 and subsequent newsletters. Practices had to be carrying out CSP using the approach described in Chapter 1 for people living with at least two LTCs. Three practices with diverse populations applied and were accepted. Two were in England, Glenpark Medical Centre in Gateshead, Trinity Health (now Unity Health) in Aylesbury Vale, and one in Scotland, Niddrie Medical Practice in Edinburgh. The characteristics of the practices and their previous experience of CSP are described in Part B.

Project commencement

A kick-off event in May 2017 brought together members of the project team, critical friends and patient representatives to ensure that the project plan had the approval of the wider stakeholders.

When asked why the project was important to them participants responses included

- Lots of people living with MSK conditions are not attended to
- This is 'the way health care should be delivered'
- People coming for CSP often want to address MSK issues
- Addressing health inequalities / meeting unmet needs / supporting professional care
- Feel it will transform care and empower staff
- Working with people with LTC to manage themselves (outside the Dr surgery)

One of the patient representatives related her personal story:

"My GP asked why I was still using sticks several months after my knee replacement – I had to remind him that I use my sticks for my chronic back problem not my knee – stop making assumptions and see me as a whole person" **Patient representative**

Early practice visits

The project team visited all three phase 1 practices to strengthen relationships, become familiar with the teams and practice organisation and clarify the project scope and plan.

These meetings were extremely valuable for both parties ensuring clarity around roles and the reporting/evaluation requirements.

Ongoing communication

To ensure we captured learning and progress in real-time the project/evaluation team and the practices held fortnightly phone calls to discuss events and progress and to share learning and solve problems.

LT also kept in touch with practices via further visits and /or phone calls to provide one-to-one support and advice and to ensure progress.

Ethics

Following lengthy discussion of a submitted IRAS application the Health Research Authority confirmed that the project did not need their approval because it involved service improvement rather than research.

Employment issues for people with MSK issues

The project was approached in August 2017 by LB as liaison lead between ARUK and DWP to inquire if the project could examine the role of CSP in supporting people living with MSK conditions around issues relating to employment and work. Although these were seen as relevant by the project team, the workload and time scales of the project, together with some practitioners concerns about the role of CSP meant that this was not pursued, though preparation prompts were checked to ensure that these issues were given equal prominence with other topics.

Evaluation

AC collected material for evaluation throughout the project by listening in, collating and feeding back her observations as a member of the fortnightly phone calls. This enriched the discussions and learning, enabling modifications to be designed and implemented.

She visited each site once between late September and early November spending most of a day with clinical (GP and practice nurses) and administrative staff and collated her findings into individual practice reports (see Part C).

The purpose of these visits was to learn as much as possible about the practices' experience of CSP and its adaptation to MSK conditions, so this could be fed into the planning of phase 2. Topics covered included

1. Identifying patients who might benefit – creating an MSK register, conditions included/excluded, applying or adapting CSP pathways, inviting patients, admin and IT support for this.
2. Content of preparatory meetings – information for patients, tests and assessments, training needs, record-keeping
3. CSP conversations – usefulness and relevance of training and materials, referrals and community support, patients' reactions
4. Follow-up and review – keeping track, re-contacting patients, IT and admin issues
5. Use of MSK-HQ and LTCQ – when, for what purpose
6. Resourcing – time, costs, benefits
7. Evaluation – what we should focus on, main challenges.

In November she supported the core team to identify the key evaluation questions and methodology for phase 2.

Phase 1 review and phase 2 kick-off event

The project / evaluation team, patient representatives, phase 2 practices and critical friends will meet in January 2018 to review the output of phase 1 and phase 2 design.

Chapter 3: practice register and recalls for phase 1

Main messages

- A short list of Read codes has been produced to identify people with the three ARUK MSK conditions (*Inflammatory, musculoskeletal pain, osteoporosis and fragility fractures*).
- Practice guidance is available to speed up what was a time-consuming process.
- People with MSK pain make up the largest group and have not previously been offered proactive care.
- Between a third and a half of MSK patients have other significant conditions / issues.
- Between 10 and 20% of patients have more than one MSK condition recorded.
- There is little in the clinical record to indicate 'activity' or functional status of individuals.
- Read codes alone cannot be used to identify those who might benefit from CSP
- Each practice decided to test CSP for different MSK populations during phase 1

This chapter describes how to identify people with MSK conditions on practice registers that are suitable to be invited to take part in CSP, and recommends a consistent approach to coding to enable new practices to introduce the learning from this project more easily. It also describes how the information currently held on GP record systems is not adequate to identify those who are most likely to benefit from CSP and begins to outline a practice strategy to address this which is elaborated in subsequent chapters and will be tested in phase 2.

Who to include in the study

The project aim was to agree a shortlist of Read codes that could be used in everyday practice and were common across the phase 1 practices. We used the three groups of MSK conditions defined by Arthritis Research UK.

1. Inflammatory conditions
2. Conditions of musculoskeletal pain
3. Osteoporosis and fragility fractures

We further refined our scope as long-term conditions '*for which there is currently no cure*' excluding conditions which are usually or often self-limiting, or where symptoms other than pain and stiffness are dominant. The main exclusions were

- Polymyalgia
- Shoulder pain
- Cervical spondylitis
- Carpel tunnel
- Plantar fasciitis

The final list for inclusion in the study is tabulated below (Read codes are listed in Part B).

| Inflammatory conditions | Conditions of musculoskeletal pain | Osteoporosis and fragility fractures |
|------------------------------------|------------------------------------|--------------------------------------|
| Rheumatoid arthritis | Osteoarthritis | Osteoporosis |
| Inflammatory spondylopathies | Back pain and non-specified | Fragility fractures |
| Gout and other crystal arthropathy | Fibromyalgia | |
| Connective tissue disease | | |

Read codes and searches

A large amount of work was required in all three practices to achieve the short list of Read codes and a consistent approach to their use.

As most MSK conditions are not included in QOF there has been no historic need to clean up or rationalise the use of codes for recall systems and this piece of work took at least the first 2 months of our programme. We have now developed guidance for new practices to speed up the process.

Arthritis Research UK Primary Care Centre at Keele University had previously identified more than 500 read codes and sub codes which could be used to identify people with MSK conditions. RB also identified a list of more than 30 read codes as potentially relevant to the Niddrie population².

An important issue was that not only were codes and sub codes used differently across practices, but often the same code was used for conditions with varying levels of impact for the person. RB reported *“It is quite clear that many of those range from entirely asymptomatic to severely disabling”*.

A further challenge was to establish whether the outputs of searches represented completed episodes or on-going issues. It was agreed to focus on people with conditions which could be identified or recorded as ‘active’ but RB noted that the Vision³ template does not allow for this so that *“a problem at age 17 could still be listed now”*. He reflected as the project progressed, that inviting people to opt into CSP was a better way of managing these uncertainties, as a number of patients declined invitations because of inactive or resolved problems.

Glenpark spent several days working through their register and produced a short list of codes (including sub codes) that all conditions had been recorded against. Even this presented a challenge and BH reported *“We found an extra 200 or so patients with gout hiding in a code filed under ‘endocrinology’ instead of MSK!”* Trinity inspected their register, starting with the list of codes from Glenpark and reported similar data. Final prevalence data for conditions of MSK pain in both practices were higher but not dissimilar to those in the Arthritis Research UK Musculoskeletal Calculator⁴ for the geographic areas of the two English practices (see Part B).

² MSK Read codes - bringing info together Aug 17, please contact enquiries@yearofcare.co.uk.

³ The 3 main GP clinical records systems are EMIS, SystemOne and Vision.

⁴ MSK calculator

Numbers identified in initial searches – please see practice data in Part B – data for chapter 4

When the first search was completed BH reflected a common perception across the practices “*The numbers seem a bit overwhelming*”. However, as the project progressed issues with the initial searches were clarified, search processes became more systematic and solutions to initial problems began to emerge.

To understand the volume of new work involved practices recorded whether the person was already within a recall system because of other issues or comorbidities. Between a third and a half of patients fell into this category implying they were already included in CSP or would be in the future. 12% (Glenpark) and 21% (Niddrie) had more than one MSK condition recorded.

Overall the numbers of people with OA, back pain and pain syndromes is larger than the other groups combined, by a factor of 5-6 in England and 3 in this atypical practice in Scotland.

Practice activity in phase 1

Each practice took a different approach to testing CSP for MSK conditions. Glenpark invited people with MSK conditions not already involved in CSP to separate MSK CSP clinics. Niddrie followed a multimorbidity approach, searching and inviting everyone with one or more ‘significant’ MSK conditions⁵ (ARUK definition) plus at least one other significant LTC. Trinity implemented CSP for RA as a single condition and as part of a multimorbidity approach.

Glenpark (practice population 9,000) searches generated 1,410 people (16% of practice population) recorded as ‘active’ across all 3 MSK conditions groups. They then excluded the 31% with diabetes/vascular disease already receiving CSP.

The Niddrie search initially included pain in the back, hip, shoulder, hand, knee, chronic osteomyelitis, synovitis, bursitis, capsulitis, cartilage disorders, cerebral palsy, spina bifida, congenital dislocation of the hip (CDH), Dupuytren’s disease, kypho-scoliosis, arthralgia, chronic fatigue syndrome, polymyalgia rheumatica, osteoarthritis, cervical spondylosis, osteoporosis, amputation, rheumatoid arthritis, gout, inflammatory arthritis, psoriatic arthritis, chronic pain, osteogenesis imperfecta, bone and muscle cancer. This revealed 828 codes.

Restricting the search to the ARUK definitions used in this project identified 534 codes in 428 patients (13% of the practice population). Osteoarthritis and back problems accounted for 74%. 54% of the total had at least one other long-term condition, such as asthma/COPD, diabetes or heart disease. Patients with gout had the highest rate of co-morbidities (70%), followed by those with fragility fractures (67%) and rheumatoid arthritis (65%).

Patients with respiratory problems were excluded while practice nurses received training in spirometry and inhaler techniques. That yielded a list of 156 patients.

Because of practice and IT system mergers during phase 1 Trinity (practice population 11,500) opted to focus on the 94 patients registered with RA using their standard birth month recall.

⁵ ‘significant’ defined as those that have a major impact on the patient’s life

Chapter 4: inviting people into the care and support planning process - MSK

Main messages

- Information gathering requirements for the different MSK groups are described
- Those with MSK pain conditions may not require *information gathering appointments* if there are no other LTCs.
- Attention needs to be given to how people are invited and how CSP is explained and language used especially if there is no information gathering appointment. Suggested examples are available.
- A strategy to identify those who might benefit from CSP (since this is not clear from the records), which includes self-identification and provides indicative numbers has been developed for testing in phase 2
- 'Intelligent templates' are available for EMIS: issues for Vision and SystemOne will be explored in phase 2
- A Read code (2JH) has been identified to record suitability for CSP when this is established.

Having agreed the codes and initial recall strategies for phase 1 the next step was to invite these individuals to take part with the aim of learning about CSP for people living with MSK conditions, including how to identify those who can benefit.

A. The principles

Who might benefit?

The central aim of CSP is to bring together the technical expertise of the practitioner with the lived experience of the person. The ARUK report suggested that CSP would benefit those with MSK conditions where there is an ongoing need for support to manage symptoms, treatments and physical and psychological consequences.

For those with rheumatoid arthritis and the fragility syndromes there is a well-defined 'professional story' already acknowledged in QOF and an evidence base for disease surveillance to prevent secondary deterioration. For those with gout and the other inflammatory conditions there are other important health issues.

For the pain syndromes, although there is no biochemical marker to monitor there is a strong case for improving function and reduced use of expensive health and social care resources both in the short term and long term via physical activity, mood and weight management. But these issues are not currently documented or reviewed systematically.

The ARUK report suggested that people might decide for themselves whether CSP would be useful. In the absence of relevant data within the records Glenpark and Niddrie opted to invite people to attend if they felt they would benefit, recognising that describing CSP in a letter cannot substitute for the experience; and that follow up of non-responders would be required to make sure that some who might benefit were not missing out.

Invitation letters

Although invitation letters were carefully drafted we learnt that in some instances wording was unhelpful. For example, at Niddrie people associated the words ‘care planning’ with the ‘Liverpool Care Pathway’ which had received a negative press. In Glenpark people who were unfamiliar with the term MSK, or didn’t understand ‘fragility’, sometimes failed to see the relevance of the invitation.

Who needs an information gathering appointment?

Most people currently involved in CSP attend an information gathering appointment which enables the tasks of condition specific surveillance to be separated from the subsequent CSP conversation. Tests results and assessments are then included, with agenda setting prompts sent to the person for reflection, as part of preparation for the CSP conversation.

For others, particularly those with pain syndromes, there is no need for an information gathering appointment, but preparation is still vital to the CSP process. Material to support this is sent one to two weeks before the CSP conversation (see chapter 5)

While the purpose of an information gathering appointment is to collect condition specific information needed by the health professional, it can also have an important role in orientating the person to the whole CSP process. The health care assistant (HCA) can describe the material they will receive, encourage them to reflect on this and record observations and questions for the CSP conversation.

The table below shows the tasks, tests and assessments needed for the different groups of conditions. Many patients with rheumatoid arthritis already attend monthly monitoring of DMARDs (Disease Modifying Anti Rheumatic drugs) and the tasks and tests for annual CSP can be incorporated into one of these visits for convenience.

Information gathering and sharing – preparation for MSK conditions

| Condition | Information gathering |
|--|---|
| Rheumatoid arthritis | Weight, height, BMI, BP, HbA1c, lipids, ESR, Smoking, alcohol Q-Risk2, Q- fracture |
| Gout and crystal arthropathy | Urates, U&E Weight, height, BMI, BP, HbA1c, lipids Smoking, alcohol Q Risk2 |
| Inflammatory spondylopathies Connective tissue disease Osteoarthritis Back pain and non-specified pain Fibromyalgia, osteoporosis Fragility syndromes | No data gathering required unless a specific ongoing test requested by specialist service |

Instructions for HCAs about which tests and assessments each person will need, and for administrative staff which appointments to make and letters to send can be written into practice protocols and ‘intelligent templates’. This was straightforward at Glenpark where MSK requirements were added to locally designed templates on EMIS Web. It was difficult at Niddrie using the Vision IT

system. Paper based approaches had to be used which would not be practical or acceptable elsewhere. The issues and templates required for SystemOne (the third GP practice IT system) will be addressed as part of phase 2.

B. What happened in practice

At Glenpark the GP or ANP reviewed the MSK lists of those born each month, who were not already attending CSP for other conditions, removing those not suitable for CSP (e.g. terminal illness, inactive or minor problem, wrongly coded). Letters were sent to the remaining patients (approximately 60 per month) inviting them to respond if they were interested in having a CSP appointment, together with an explanation (see Part B).

Around a third of patients expressed interest (5-6 per week) and the administrator either sent them a 20 minute CSP appointment (along with preparation prompts – see chapter 5) or, if they had gout or RA, an appointment with the HCA for information gathering. Test results were sent out 1-2 weeks later together with the prompts and the CSP appointment. The results sharing leaflet is printed on yellow paper, so the person can identify it separately from other post they may receive and which they may potentially be less happy to open.

Thirty seven CSP conversations were completed for patients with MSK conditions alone and birthdays in June or July.

The numbers involved in this process and information held in the records on the 40 non-responders is shown in Part B. The practice administrator rang 21 who had declined the invitation and the reasons they gave are also included.

The challenge for Niddrie was to engage people in a population where the problems of day to day living often overwhelm traditional condition specific issues and attendance for systematic or preventive health is poor.

Batches of letters inviting patients to an information gathering meeting were sent out each week to those on the MSK list, in alphabetical order. The letter was personalised from the patient's usual doctor. The initial response was disappointing but, as the wording was changed and the volume of material sent out reduced, this improved. Changing the heading from 'care planning' to health planning' also seemed helpful.

RB reflected that *the "more information I send patients the less they become involved"*.

By September 150 invitation letters had been sent and 42 patients had attended both a preparation meeting and care planning discussion with their usual GP. A further 10 patients had made appointments for preparation meetings (35%).

The team picked up anecdotal reports from non-responders such as *"didn't understand what it was about, doesn't apply to me, didn't open letter, low expectations of health"*.

The team's goal is to see 20 CSP patients each week, 1,000 in a year. They reflect that in the future newly diagnosed patients could be picked up opportunistically and they would flex their systems to allow more CSP consultations in the summer months when the workload is a little lighter.

At Trinity patients with RA are sent a letter including prompts and questionnaires in their birth month telling them what type of appointment they should book, with whom and what to expect (approximately 2 per week). They have been familiar with CSP for some time, attendance is good and non-attenders infrequent.

Chapter 5: preparation for CSP-MSK

Main messages

- Patients with MSK conditions appear to value preparation highly (as reported by patients with other conditions) and is discussed in Chapter 7).
- Prompts and information sharing leaflets and resources have been developed for MSK conditions.
- Practices used slightly different preparation tools, but all included open questions, agenda setting prompts and routine test results where appropriate, with explanations
- Practices used a range of patient completed material to provide information on aspects of MSK health and function for the professional including locally produced material and the MSK-HQ
- Phase 2 will explore the balance between generic and condition specific prompts and the tension between the need for information and the volume of material, in the context of multimorbidity.

The key element that distinguishes the YOC model of CSP from other models is preparation for the person (and their carers) and the practitioner who is going to take part in advance of the conversation.

The benefits are

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

Preparation for the person

Preparation for the person involves receiving personally relevant clinical information (perhaps collected at an information gathering appointment) laid out in a specifically designed leaflet with explanations, together with agenda setting prompts for reflection prior to the conversation.

Preparation for the practitioner

The practitioner needs to collect information from all sources and arrange for any tests, questionnaires or assessments to be made. It is increasingly recognised in CSP for other conditions that the person themselves is often best placed to complete this via self or supported administration of questionnaires. This has the additional benefit of focussing the individual on symptoms and other activities which add to a rich pool of material for reflection and support for self-management.

Chapter 4 describes which MSK conditions need an information gathering appointment as part of the professional and patient's agenda. Chapter 7 discusses the potential role of the MSK-HQ as additional preparation for the person, or the practitioner or both.

Designing YOCP prompts for people with MSK conditions

YOCP developed new resources for this project using feedback from the MSK user group and working with the Lead Rheumatologist in Northumbria Healthcare NHS Foundation Trust, Dr Iain Goff. These are shown in Part B and include

- A folded A4 sheet (A5 pages) for information sharing in which page 1 includes open questions such as ‘*What important issues would you like to discuss?*’ ‘*What is important to you?*’ and a “noticeboard” of common issues to prompt reflection. It invites the person to circle any that are important to them.
- The folded centre is used to share test results with short explanations of the healthy range, and has the potential to show trends and add comments.
- Page 4 provides an opportunity to begin goal setting and action planning if the person thinks that is relevant.
- Separate, explanatory condition specific leaflets based around the behaviours that could be modified to make a difference to that condition (self-management); included to enable the person to start the process of reflection.

Prompts used in practice

At Glenpark the relevant resources together with the MSK-HQ were sent to all patients either with the invitation letter or after the information gathering appointment and embedded into IT systems.

Niddrie designed local information gathering tools and prompts, which they gradually simplified. A ‘front sheet’ with an open question about how they were coping, and a comprehensive notice board were sent out with the initial invitation to phone to make an appointment. Where an information gathering appointment took place, results were discussed at the weekly team meeting before being entered on the information sharing leaflet, which was sent to the person with an appointment for the CSP consultation.

Trinity used YOCP material previously developed as generic (i.e. non-condition specific) prompts which they adapted locally in consultation with practice’s patient participation group. Sent out with the invitation letter this includes a *What is Care Planning leaflet?* an ‘agenda setting prompt’, and a self-assessment tool (covering activities of daily living, physical health, thoughts and feelings, care and support, lifestyle, health care issues). Where there are comorbidities the HCA organises relevant tests, explains the CSP process and makes the appointment for a CSP discussion with a nurse about 2 weeks later. Currently there is no RA or MSK specific material in use.

Chapter 6: using the MSK-HQ and LTC-Q

Main messages

- It was not possible to link the MSK - HQ directly into clinical systems, and unforeseen developments prevented electronic entry or presentation of results; but there was much useful learning to be explored further in phase 2.
- This learning may be influenced by the way the material is presented and administered. This will not be possible to test within this project.
- Important questions which can be explored using paper formats include
 - The role of the MSK-HQ as a patient prompt
 - The role of MSK-HQ as a practitioner 'prompt' within the conversation
 - The effect of condition specific compared with open prompt questions on the content of the conversation especially in a multimorbidity context
 - MSK-HQ a useful way of collecting and recording functional data for use in other practice activities
 - The potential of using MSK-HQ to identify who might benefit from CSP
- The format of the LTCQ makes it less suitable for use within the conversation, but its more generic questions might be useful in a multimorbidity context.

Background to questionnaires

MSK-HQ is a validated 14 item questionnaire (see Part B) developed as a PROM to assess treatments and other interventions for people living with MSK conditions. The ARUK report *Care planning and MSK Health*, suggested it might also be useful for people to self-assess their MSK health, support self-management and shared decision making, and to share information between HCPs. The MSK – HQ became available at the start of the project and it was decided to test these suggestions within the CSP process.

LTCQ is a recently validated 20 item PROM specifically developed for people living with LTCs also available for use in the project. We were keen to know whether one questionnaire proved more useful than the other; whether they were complementary, especially for those with multimorbidity; if they 'got in the way' of the CSP process; and if electronic collection and analysis affected their use and acceptability to patients and providers?

Specific roles in CSP might include

- As a prompt to prepare for the CSP conversation?
- As a tool to use for discussion within the CSP conversation?
- As an ongoing self-assessment tool after CSP?
- As a PROM for CSP, administered at baseline and then repeated at future intervals?

Using the MSK – HQ in practice

“Let’s test things rather than assume (e.g. technology for the MSK-HQ and LTCQ)” **critical friend, GPwSI MSK conditions (Giles Hazan)**

Phase 1 explored this from two perspectives. The first considered the potential of using the PROMAPP platform where MSK-HQ is already established; to enable people with MSK conditions to complete the questionnaire electronically and results to be available both at practice level during CSP and directly to the person (in a variety of formats) for self-management and individual progress assessment.

The second was to see how useful this information was as part of preparation for the CSP conversation and during the conversation itself. Both questionnaires were taken to the Gateshead Arthritis Support Group. Participants were positive and divided 50/50 as to which questionnaire seemed most useful.

It became clear early on that direct links between the PROMAPP platform and primary care IT systems would not be possible. Presenting results in a different way was also not progressed because of the untimely death of Toby Knightly Day – the project lead for this part of the programme.

Using the MSK-HQ and LTCQ in CSP

The MSK-HQ was used in paper form at Glenpark and Niddrie as part of the CSP process. This '*proved clunky*' and would not be suitable for routine care. In late September both practices agreed to ask people who had CSP in June and July to complete it again 'as a PROM'. The results of this are awaited.

Trinity administered the MSK-HQ to participants before and after the local 'Use it or Lose it' group as a traditional PROM.

Glenpark changed to administering LTCQ instead of MSK-HQ in the last month of phase 1.

Despite difficulties there is already some useful learning which will be developed further in phase 2. A full evaluation of the roles of these questionnaires within CSP will require smoother electronic entry and presentation of results and would need to be taken forward as a separate project.

At Glenpark the MSK-HQ was sent out with other prompts including the information sharing (test results) letter and roughly half were completed. There was no explanatory information about its purpose or what the results meant and no local tailoring of the format. Completed questionnaires were brought to CSP conversation appointment, then scored manually and scanned into EMIS-Web using a specific Read code to record completion and the individual score.

At Niddrie the MSK-HQ was initially included in the invitation paper work and a few were completed. In a desire to reduce the volume of material sent out, the receptionist started to support individuals to complete it in a private room when they come to the conversation appointment. It was completed by about a quarter of patients having CSP conversations. Completed questionnaires were scanned into the clinical record and planned to be entered on a laptop for inclusion in PROMAPP. In practice only one record was entered reflecting the everyday reality in which key staff go off sick and there is very little time allocated to tasks such as batch entry of data.

Role of the questionnaires in the conversation

Comments on the role and benefits of the MSK-HQ varied between in Glenpark and Niddrie, with the former commenting mainly on patients' perceptions and the later on benefits for the professional in their multimorbidity clinics. This may have been influenced by completion of the questionnaire immediately before the conversation at Niddrie.

In Glenpark BH looked at the MSK-HQ in its paper form at the end of the conversation and rarely found it added anything to what had already been discussed. Staff reflected that it might have helped patients' think about their goals and priorities prior to the meeting. Some patients reported it was hard to complete because it refers to the previous two weeks and doesn't acknowledge that symptoms and function change from day to day. One patient said it felt like a test with right or wrong answers. They were more positive about and had often completed the generic YOC prompt.

RB used the MSK-HQ as a 'professional' tool to assess patient function in consultations. He noted that, although patients are encouraged to discuss whatever they want to, it could be a conversation starter, give an idea of the extent of disability and could alter the direction of the conversation towards MSK issues (see Chapter 7). The disadvantage is a potential bias towards discussing MSK, while the open YOC prompt is designed to capture a much broader range of issues. These issues will be explored further in phase 2.

Glenpark stored the MSK-HQ in the clinical record because it provided functional information about patients' problems and was useful when completing benefit forms. A concern is that this use may not be directly apparent to the person when completing the questionnaire.

RB suggested to two patients in August that they share the MSK-HQ with their long-term disability assessor for benefit renewal at DWP. He felt this could support their assessment, but no feedback is yet available.

Glenpark started using LTCQ in September and immediately noted that the item format (least affected to most affected varies left to right) made it difficult to review quickly in the clinic setting. They plan to use it as a baseline PROM for the remaining months of 2017 and re-administer it to phase 1 patients in autumn 2018 at the end of phase 2.

Baseline information from MSK- HQ

11 MSK-HQ questionnaires were available from Glenpark and 11 from Niddrie with the linked narrative of the conversation available from Glenpark (see Part B for distribution of scores). Low MSK-HQ scores indicate a greater negative impact of MSK conditions on wellbeing.

The values recorded for Niddrie were almost universally higher than those for Glenpark but the difference didn't achieve significance (mean (SEM); 31.5 (4.0) vs 21.8 (3.3) $p=0.07$) probably because of small sample size. There was a greater range of scores (both lower and higher) at Niddrie. Looking at the linked Glenpark narratives, the lower global scores seem to have been in people with loneliness, depression or significant loss of function and raises the question of whether the MSK-HQ might be involved in determining who could benefit from CSP within a given population. This will be explored further in phase 2.

The MSK-HQ was designed to allow people with MSK conditions to report symptoms and wellbeing in a standardised way, and to measure the impact on these of health services and interventions over time⁶, however normative data for matched primary care populations of people with MSK conditions are not available, although there is a rapidly expanding literature about its use. Glenpark and

⁶ Hill JC, Kang S, Benedetto E, et al

Development and initial cohort validation of the Arthritis Research UK Musculoskeletal Health Questionnaire (MSK-HQ) for use across musculoskeletal care pathways
BMJ Open 2016;6:e012331. doi: 10.1136/bmjopen-2016-012331

Niddrie explored a different use of the MSK-HQ, as a preparatory tool for CSP conversations. They used different approaches to administering the MSK-HQ which may have influenced scores. The use of the MSK-HQ as a preparation tool will be explored further in Phase 2.

Trinity used the MSK-HQ global score as a PROM before and after the 'Use it or lose it' intervention and showed improvements. We noticed that there are complex interactions between domains of the MSK-HQ some of which are disease dependent and some of which reflect personal circumstances, resilience, knowledge and skills. Each of these might be improved by CSP and before and after scores for 3 months CSP at Glenpark and Niddrie are awaited with more planned for phase 2.

Chapter 7: CSP in MSK – the conversation

Main messages

- Most practitioners found the conversations worthwhile and valuable and reported positive comments from patients
- The length of the conversation is variable; median 30 minutes and some much longer.
- CSP conversations can be carried out by a variety of practitioners as long as they are trained in CSP (and MSK conditions) and are well supported
- The preparation stage of CSP enables previously undisclosed topics related to symptoms, daily living and overall function to be raised. There was much unmet need which would not have been identifiable from the records
- There was a wide range of topics discussed in the conversation – pain was a common issue.
- Work related issues were rarely raised despite these being included in prompts
- There was always something to be done as a consequence of the conversation. Actions varied widely and included referral, reducing medicines and signposting
- Practitioners suggested subsequent CSP cycles might be less time consuming, and maybe less often than annually, once long-standing health issues had been resolved and everyone was more familiar with the process. They were prepared to invest the time now for future gain.

Who was involved in the conversations?

The practices adopted different approaches. At **Glenpark** the focus was learning about CSP in MSK conditions without the distraction of other comorbidities, and included people with the full range of MSK conditions. The conversation appointments were carried out by the lead CSP GP (BH) or the advanced nurse practitioner (AK). Both were experienced CSP practitioners and YOC trainers and worked together on triage and reflection. No issues were raised by patients which AK could not handle and they both felt that it should be feasible for practice nurses to conduct these meetings, provided they are Year of Care trained and well-supported, with opportunities for GP debrief and mentoring. The appointment is usually at the surgery but could be at home for a housebound patient.

In **Niddrie** where continuity is a central component of practice ethos each person was seen by their named GP. In the future the HCA or practice nurse who lived in the community might be involved, with GP supervision. The practice approach is that encounters should be open and flexible, so all staff support patients to reflect on the day to day and social issues that often dominate their agendas. Some patients wanted to discuss all their issues in the first data gathering appointment, and the differing functions of the CSP appointments and staff roles may get blurred.

At Trinity patients with RA are seen either by a practice nurse they know well as part of a multimorbidity approach, or their regular GP if they have RA alone. All staff have had generic CSP training, but nurses have not been trained to handle RA specific issues and don't necessarily feel confident to do so. It is planned for a local rheumatologist to provide some training. Clinical supervision is provided, and complex issues are discussed at team meetings or referred to one of the GPs.

Time spent on the conversation appointment

Although all practices had a flexible approach to booking time for CSP conversations depending on expected complexity, the project quickly learned that this could not be reliably predicted for MSK patients because records lacked essential information on disease activity, living with the condition, functional status, self-management or issues such as anger and low mood.

Some consultations were shorter than expected.

“We already encountered one problem we did not anticipate: A patient with spina bifida, osteoporosis and arthritis, AKA as the perfect patient for the study, came for a CSP appointment and was a little bemused about the fact that we would want to support her in self-managing her condition. She had done this very successfully herself for the past 70 years without much GP input and feels she has all the support in place that she wants. I suspect there will be a few like her” **RB**

In both Niddrie and Glenpark the majority took longer than the practice ‘standard’ of 20 minutes with a median of 30 minutes at Glenpark and a few extending to 40 minutes or more. One reason cited was the novelty of this approach for both staff and patients because neither had experience of regular recall as part of QoF and at Glenpark none had experienced CSP previously.

Patients with painful conditions who had not had an information gathering appointment and face to face explanation were not always clear about the purpose of CSP.

“One lady had had a hip replacement many years ago thought she was just coming to collect her tablets and hadn’t discussed her issues with any one” **BH**

Practitioners suggested subsequent CSP cycles might be less time consuming, once long-standing issues with practical solutions had been resolved and everyone was more familiar with the process and its purpose. They were prepared to invest time now for future gain.

Content of conversations

All practitioners found the conversations worthwhile and reported positive comments from patients.

So, I did my first MSK CSP clinic this morning.

Wow.

The phrase "opening Pandora's box" came to mind.

There is absolutely no doubt in my mind that this IS a forgotten/ neglected group.

Apart from one man, who had no problems with his Osteoarthritis but used the opportunity to sort out some other medical issues, the other 5 had some extremely complex problems which were totally not apparent from a quick look at their records. 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.” **BH**

From July onwards, the project asked practitioners to complete a short reflective sheet immediately after the conversation.

These document the vast range of patients’ concerns, and the variety of issues covered in addition to specific MSK symptoms, including impact on daily activities, loss of independence, sleep problems, overweight, anxiety and depression, financial problems and benefits claims, mobility problems, migraine, incontinence, loneliness, family stress, hypertension.

Comments indicate that these CSP-MSK conversations were well-received by patients, revealing hitherto unmet need and low expectations of health services. They appreciated the chance to talk about their problems, some indicating that no one has listened to them in this way before. Several misperceptions have been revealed, for example the belief that nothing can be done for pain/mobility problems, or that exercise will exacerbate the risk of falling and/or increase pain severity. A few patients have revealed themselves to be effective self-managers requiring no further intervention.

“They had never talked about issues”; “they had just been getting on with it” BH

“Many patients in this area are fatalistic about their health, with low expectations. They are not used to feeling empowered or self-directed in any aspect of their lives, so the idea of self-managing their health is a totally new concept, sometimes greeted with hostility – “How do I know? – you’re the doctor!” However, the team has noticed that new ideas do eventually take hold and the benefits of signposting people to local resources can multiply in a ripple effect as trust builds.” Niddrie

Practitioners said the conversation felt very different from previous CSP in QOF conditions with less goal setting and action planning - though perhaps that was because these were first visits with “a lot to sort out”.

RB noted a much wider ranging discussion than in previous QOF reviews. This was partly because the abolition of QOF in Scotland removed a perceived imperative (financial penalty) to concentrate on biomedical outcomes. This less pressured conversation could focus on what was important to the person, bringing in the information on social issues, housing finance etc. that was known to (and collected) by the practice but not usually discussed with the doctor. For instance, the focus on MSK (sometimes alerted by the presence of the completed MSK-HQ – see chapter 6) could enable a more productive and engaging discussion around weight management for symptom relief rather than HbA1c control.

However, MSK issues were not always more prominent in multimorbidity discussions and the issue of how to ensure that they were not neglected out of habit, lack of training or relevant skills needs further exploration. At Glenpark use of the YOCP ‘open’ prompts enabled issues to be raised that had not been discussed before, and broadened out the discussion from its traditional disease focus. Many, but not all, had made notes on the prompt sheets and half had completed the MSK-HQ.

Pain was the commonest topic in the conversations (at Glenpark) reflecting the predictions of the Arthritis User Group. However, it was not consistently mentioned in the records and had often been omitted from other practice consultations despite analgesics being a common medication. Some people had become active self-managers.

“A lady with MSK had read a book on living with chronic pain, she had realised that she wasn’t going to be cured, treatment options minimal and therefore had to live with the symptoms. She stopped her pain killers and changed her mind set and perspective on life – I reflected about the importance of having honest conversations with some patients with MSK conditions regarding living with pain rather than curing pain.” BH

The project had expected work related issues to be a prominent topic in CSP conversations. A previous study in Gateshead of people living with LTCs had suggested that people would value this. However, although work related issues were included in the YOCP prompt as well as the MSK-HQ

they were not raised in any of the Glenpark conversations. More detail on age and employment status will be collected in phase 2 to help understand this discrepancy.

Outputs from the conversation

BH reported 'there was always something to be done as a consequence of the conversation' whether it was reducing medicines or signposting. People with RA usually had health problems already sorted out. Those with pain syndromes who had not been part of proactive review often had issues which once dealt with might not need a yearly review. For instance, one person was referred for further assessment since the recorded diagnosis was in doubt. In another the person was referred for an OT assessment which happened within 2 weeks with aids fitted to her home within a further week.

"Usually you come in, get tablets, go out and think 'is this it?' It's so helpful to talk" **(This person had medicines reviewed, was referred for ultrasound and to Thai Chi taster)**

"You accept nothing can be done so you struggle and live with pain and don't bother mentioning it to the doctor as there seems no point" **(This person was given Gabapentin for pain relief and referred to a befriending service)**

The variable outputs reflected the wide-ranging discussion which took place. Actions included provision of practical support, adjustment of medications, provision of aids and adaptations, referral to befriending service and other local voluntary groups, to social care, to the pain team, and to CAB for benefits advice, support for healthy eating, and just listening. All three practices noted that patients appreciated the 'More than Medicine' approach, but highlighted issues of availability, access and short-term funding.

Patients were asked when they would like to be reviewed. At Niddrie responses ranged from 6 months to 5 years and a specific review date was set. At Glenpark some patients needed no further follow up, others needed early review if management changes had been made. The remainder agreed to be involved again, in multimorbidity CSP clinics if they had co-morbidities, with a default option of 12 months.

After the consultation BH corrected coding inaccuracies and began to use a specific code (2JH) to indicate suitability for ongoing cycles of CSP.

Chapter 8: training issues

Main messages

- Learning about the conversation is based on self-reports
- Experienced practitioners reported that core YOC training enabled them to feel confident in carrying out CSP for people with MSK conditions
- Some practice nurses were less confident both about generic CSP skills and condition specific content reflecting experience reported in other CSP projects.
- The centrality of pain and relative inexperience among practitioners in systematic, holistic and skilful approaches to prevention and management, linked with better community support is emerging.
- None of the current courses aimed at primary care team members meets the needs of CSP practitioners to support and discuss the topics and issues raised by people with MSK.
- It is proposed to examine all these issues in depth in phase 2 with the aim of providing guidance for ARUK on future training needs.

Core training in CSP is focussed on engaging practices in a new way of working that involves changes to attitudes and ethos of working with people with LTCs, and helps to develop the generic skills and clinic infrastructure needed to support a different kind of conversation.

Practitioners also need to be knowledgeable and confident in discussing condition specific issues including 'red flags', common medications, groups of symptoms, FAQs, contingency packages as well as the emotional and mental health issues common in people living with LTCs. They need to know about local referral pathways, and how to link with supportive community activities.

These skills vary across different professional groups and individual practitioners depending of levels of core and advanced training and experience.

For the most part, the staff involved in phase 1 were experienced YOC CSP practitioners and /or trainers, and thought core YOC training providing a good grounding. They reported that they could use their generic CSP skills in conversations with people living with one or MSK conditions.

Practice nurses at Trinity had already identified the need for specific training in RA and this was being organised locally. They also noted that CSP represented a major change of approach from their traditional training in a more protocol-driven medical model and reported occasional difficulties. These included getting patients to understand the purpose of CSP meetings and/or to focus on the issues and knowing when it is appropriate to give advice and when it isn't. Appointments sometimes overrun their allotted time if they found it hard to close the conversation.

The subjects highlighted by patients as being of most importance to them, including pain, anxiety and depression and social issues were those that surveys in other CSP projects found practice nurses had most difficulty with. These would form important elements of a training programme for MSK conditions and arguably are just as relevant for CSP for everyone with LTCs.

Currently ARUK and RCGP provide comprehensive training and courses in MSK conditions for GPs, medical students, prescribers and those practitioners that need to make a diagnosis. These provide background physiology, presentation of disease, diagnostic criteria and medical management. They cover most common MSK conditions and may provide practitioners with CPD points.

There is less training designed specifically for nurses though some of the medically orientated training includes information that would be essential for CSP and ongoing management; red flags for some conditions and suggestions for symptom relief. Some cover aspects of pain management but no training addresses mood. There is also little about supporting the person with functional issues or the value of non-traditional or alternative management options.

Other issues identified in phase 1 such as weight management, medicines advice and listening to people who wanted to be listened to would be regarded as core nursing skills and acquired throughout their training. But GH advised that there are common misconceptions specific to MSK that should be addressed in training e.g. the fear that exercise may make the condition worse and the use of unhelpful language such as 'wear and tear'.

BH contacted the local pain relief services and reflected that a great deal more could be done. This might include developing additional skills for use in the consultation but also raising awareness across the practice of how to refer the person for ongoing support when pain syndromes first present, as part of medication reviews and when it becomes an ongoing issue. She sought out and attended further training which confirmed her view that despite being an experienced practitioner there is more she could learn.

Chapter 9: links with wider community - more than medicine and specialist services

Main messages

- Links with local specialist services are important in developing high quality CSP in general practice
- Practices involved in this programme already make good use of social prescribing in their general CSP work and CSP for people with MSK conditions were no different with people benefiting from a range of “non-traditional” support offers.
- Conversations (Chapter 7) identified mobility issues, and social isolation and pain as important issues for support
- There was haphazard availability and long-term insecurity for community activities
- It would be useful in phase 2 of the programme to capture the proportion of referrals and signposting to more than medicine activities.

One aim of this project was to explore how CSP would fit in the wider local context. Part B displays the local services around Glenpark as an example of how specialist, community and voluntary services are important at every stage in the pathway for the person with an MSK conditions from diagnosis to lifelong CSP.

Although usually not involved directly in individual CSP, specialist services have an important role in supporting general practice teams. Chapters 4 and 8 recognise the importance of content knowledge in information gathering and for the practitioner within the conversation, implying a supportive role for local guidelines and specialists. Trinity is calling on the expertise of local rheumatologist for training those involved in the CSP conversations. Glenpark has made referrals to OT and community nursing as outcomes of the CSP conversation. More explicit links will be explored in phase 2.

All three practices described the importance of local community support in addressing specific MSK related symptoms such as pain management and exercise, and more general issues of loneliness and low mood (chapter 7). Each had made specific endeavours to develop local links (Part B). They all reported frustrations with short term funding, piece-meal projects not always in the right place and inability to access potentially helpful activities by those with poor mobility. No site had a locally commissioned coordinated approach to develop and sustain ‘more than medicine approaches’ though some activities were excellent.

Despite the very different demographics, all sites found that activities linked directly into the practice were most useful either because of lack of public transport (Trinity), deprivation (Niddrie) or immobility (Glenpark). Please see Part B.

In Glenpark the practice administrator acts as the social prescribing link. When a person is identified who would benefit from services outside of the NHS, such as befriending service, exercise classes, local patient groups, she phones to signpost them to appropriate services and will occasionally take them along to introduce them.

Niddrie reported that although there are excellent local services such as Thistle Foundation’s Centre for Wellbeing, patients preferred practice-based initiatives such as the wellbeing practitioner who was based there until his funding ran out. The practice is expecting to be involved in several other

local initiatives, but most of these are time-limited – short-termism and constant change in the system is an obstacle for effective care planning.

Trinity had obtained local short-term funding to develop a course “*Use it or lose it*” in one of the local communities without public transport. Based on the ‘*Escape pain*’⁷ approach a clinical exercise specialist works with people identified by the practice to improve mobility, reduce pain and increase confidence. The course ran over 12 weeks and included individual assessment and group activities. The project used the MSK-HQ at the beginning and end to show improvements and recorded many positive comments including

“I am always falling and often I have to call for an ambulance because my husband has dementia and is not very strong. I fell in the garden and followed the things we’ve been taught and got myself into a sitting position then had a rest then got myself standing up. It wasn’t easy but I did it.” **Person with**

MSK condition

⁷ <http://www.escape-pain.org/>

Chapter 10: evaluation and impact to date

The logic model developed at the start of phase 1 is shown in Part B.

A number of practical questions were developed early in the project and have formed the basis of phase 1 evaluation.

1. Did practices manage to implement and embed CSP successfully?

Progress in phase 1:

Practices were able to implement CSP and show that core components are suitable for people living with MSK conditions.

The preparatory work to clean registers was time consuming and guidance to shorten the process is now available.

MSK specific resources for call and recall, invitation and preparation were produced, and practices used these and locally adapted modifications.

There was a consistent and clear recognition that adopting CSP for MSK conditions identified a level of unmet need which could be addressed through this approach.

Implications for phase 2:

The large numbers of people with MSK conditions, (especially OA and musculoskeletal pain syndromes) identified from registers and not previously included in proactive have implications for embedding CSP for all. There was not enough information in the records to establish if some people might benefit more than others and a strategy to develop this was proposed.

These issues will be explored in phase 2 along with transferability of learning and resources.

Nearly half of patients had other LTCs so phase 2 will use a multimorbidity approach to CSP.

2. How does the experience of this differ from CSP implemented for other conditions?

Progress in phase 1:

In comparison to QOF conditions, people with MSK conditions report these are seldom asked about these and as a result the concept of CSP was enthusiastically welcomed.

In common with other conditions people valued very highly the opportunity to prepare for and have a different sort of conversation. Staff recognised this, and were positive about the shift in the emphasis towards a more person-centred consultation for this population.

Not all MSK conditions require a pre-conversation visit for tasks and tests to be performed with subsequent information sharing. This reduced the opportunity to orientate patients to the CSP process and together with identifying unmet need meant that consultation times were sometimes longer than in other conditions. It was unclear if this would continue to be the case in subsequent CSP cycles with the same person.

The optimal interval between CSP consultations (usually annually with QOF conditions) may be more variable with MSK conditions and it is unclear if this will be related to the specific condition, the degree of disability, or individual skills in self-management.

Implications for phase 2: There will be a systematic approach to capturing data on these issues and experiences from people and professionals via consultation reflection sheets, a more detailed recording of resource use and in-depth records analysis over a two-month period. The current cohort will be reviewed 12 months later.

3. What resources are required to implement and embed CSP for MSK?

Progress in phase 1:

As with other conditions resources are required to support preparation of patients and practitioners and new practice processes.

MSK specific Read codes, information gathering, and administration templates have been developed and are available for EMIS-Web.

MSK specific letters, reflective prompts and information sharing resources have been produced.

The relative merits of different practice approaches and resources (including use of MSK-HQ), to collect information on symptoms and function for use in CSP and inclusion in the clinical record needs further exploration.

The importance of initial and ongoing MSK specific training as well as reinforced CSP skills has emerged.

Wider 'more than medicine' activities in the community are helpful for many following the CSP conversation and are not always available.

It is not yet clear what additional resources are needed to offer CSP to all those who might benefit or whether this might be offset by a reduction in use of medicines or other resource use within the practice.

Implications for phase 2: phase 2 will refine the additional resources needed, explore training needs in depth and begin to explore practice wide resource use.

4. What are the pros and cons of using PROMS (the MSK-HQ and LTCQ) as part of the CSP process, how might they be most useful and how do they differ?

Progress in phase 1:

The inability to complete the MSK-HQ remotely and transfer the results into existing GP electronic records has been an obstacle to testing its optimum use.

However, its role in preparation for CSP conversations, and as consultation prompt within CSP conversations has been observed. Practices have found value as a 'checklist' for health professionals in those with multiple long-term conditions to ensure that areas of perceived MSK difficulty are addressed in consultations. However, this may affect the conversation both positively and negatively in a multimorbidity context. Baseline values have been reported.

Initial observation of the LTCQ, in the limited time available, suggests that the item structure may not be suitable for a clinical context. However, in a multimorbidity context where the focus is the person rather than any one condition this questionnaire with its more generic items may be more useful.

Implications for phase 2: phase 2 will record the use of MSK-HQ in paper form as a preparation tool for each person. It will be used as a PROM at 6 months on a 2-3-month cohort and be administered to those who completed it in phase 1.

Baseline LTCQ will also be collected to extend experience with its use and as baseline for repeat in potential future studies.

5. How can e-PROMs (MSK-HQ and LTCQ) be collected and used routinely as part of CSP for people with MSK conditions?

The difficulties encountered in Chapter 7 meant there was little progress in the technical issues of using these PROMs and it has been accepted by ARUK that this will need to be taken further in a separate project. However, there was much useful learning about the use of the questionnaires in CSP process as outlined above which will be elaborated on in phase 2.

Acknowledgements

With thanks to:

Arthritis Research UK

Arthritis Support Group Gateshead

David Gilbert, Patient Director for the Sussex MSK Partnership

Dr Iain Goff, Consultant Rheumatologist, Northumbria Healthcare NHS Foundation Trust

Also thanks to the practices and their patients for taking part in phase 1 and their ongoing support with phase 2.

Part B – The Data

Part B of this report provides detail for those moving to phase 2 and the data from which conclusions were formed in Part A.

Data for Chapter 1: project brief and background and approach to evaluation

Recommendations from section 7.1 of the ARUK Document ‘Care Planning and Musculoskeletal health’

Care planning is an approach that helps people with long term conditions to manage their health and wellbeing. National policy states that ‘everyone with long term conditions ... will be offered a personalised care plan’. People with musculoskeletal conditions and people who have musculoskeletal conditions and other multimorbidities are part of the wider spectrum of people with long term conditions that can benefit from care planning.

Arthritis Research UK is working to ensure that musculoskeletal health is included in all care planning discussions and that the benefits of care planning are realised by people with musculoskeletal conditions.

Recommendation 1: Healthcare commissioners including NHS England should ensure that care planning is available to people with musculoskeletal conditions. This includes people with inflammatory arthritis, conditions of musculoskeletal pain such as osteoarthritis and back pain, and those who have had a fragility fracture.

Recommendation 2: Systems for delivering care planning must be designed to ensure that people with musculoskeletal conditions are offered care planning, and to systematically identify and address musculoskeletal needs in people with any long term condition.

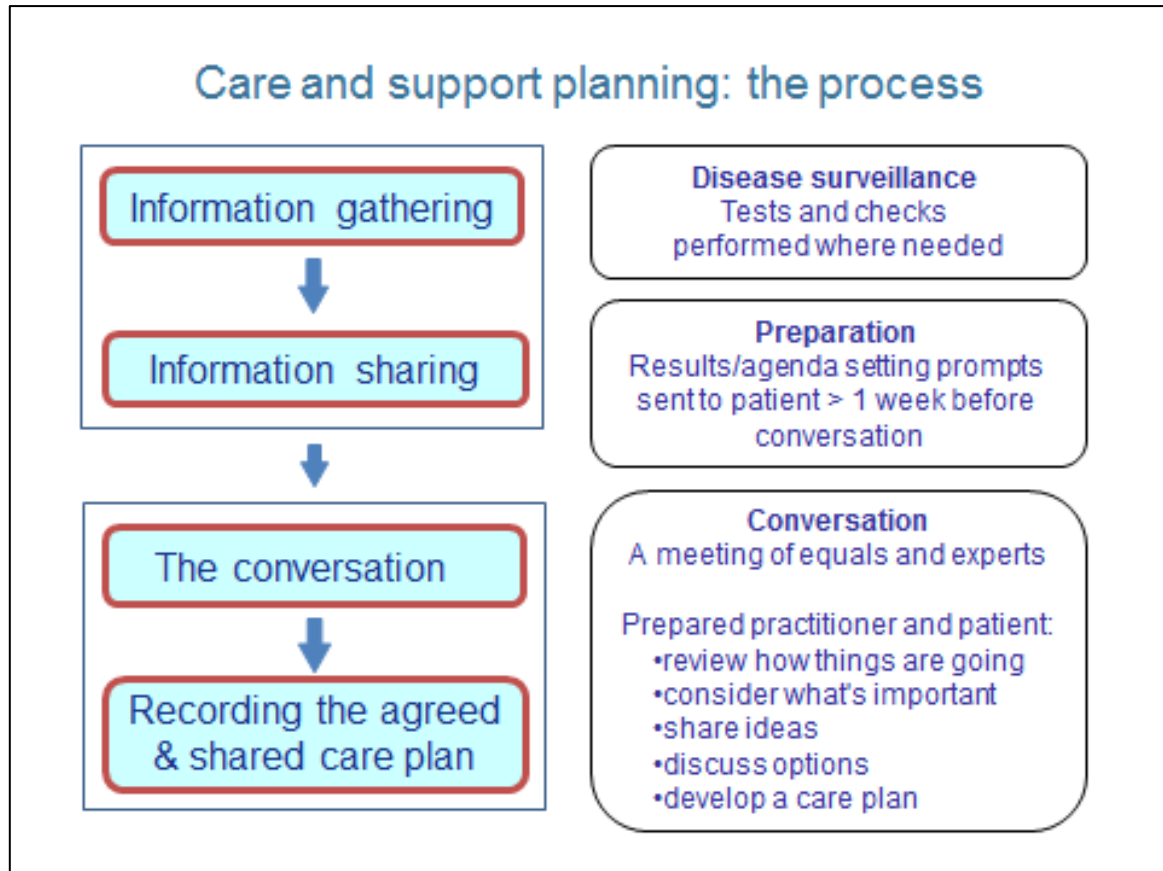
Recommendation 3: Professional bodies must ensure that healthcare professionals involved in care planning have relevant training, including in musculoskeletal core skills. Healthcare professionals should ask about musculoskeletal pain during care planning where appropriate, should consider how the person’s function, mobility and wider health and wellbeing are affected, and should understand interventions to enable people to improve their musculoskeletal health.

Recommendation 4: Commissioners of healthcare services, including local authorities, should ensure the provision of local services and facilities for people to use in achieving the musculoskeletal health goals agreed during care planning.

Recommendation 5: Evaluation of care planning on people’s experience of healthcare and on their health outcomes should continue as care planning is more widely implemented. The health economic value of care planning including in those with musculoskeletal conditions and multimorbidities should be further established.

Recommendations 6: The Health and Social Care Information Centre (HSCIC) should publish by medical condition (including musculoskeletal conditions) data on ‘the proportion of people with a care plan’, alongside the ‘proportion of people feeling supported to manage their conditions’.

CSP process – practical details



Data for Chapter 2: how we went about it

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 will lead the project and retain oversight throughout phases 1 and 2 |
| Co-applicant | Angela Coulter | Senior Research Scientist, University of Oxford | Angela will lead the overall evaluation 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 will be the project's Clinical Lead and provide support for clinical developments |
| Co-applicant | Sue Roberts | Chair, Year of Care Partnerships | Sue will be a core member of the project team and will offer her wealth of expertise in care and support planning |
| Year of Care Partnerships Project Manager | TBC This person was later confirmed as Lucy Taylor | TBC Operational Support Manager, Year of Care Partnerships | The Project Manager from Year of Care Partnerships will be responsible for coordination and management of all elements of the project for the 21 month duration |
| Year of Care lead trainer | Lesley Thompson | National Trainer and Assessor, Year of Care Partnerships | |
| Evaluation team | Toby Knightley-Day ⁸ | 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 |

⁸ Toby Knightley-Day sadly died unexpectedly in July 2017.

| | | | |
|---|---|--|----------------------------------|
| | | | deploy the MSK-HQ and LTCQ PROMS |
| Critical friends | | | |
| Sarah Cowling | Chief Executive, HealthWORKS Newcastle | | |
| Kate Croxton | ARUK Head of Professional Engagement and Strategic Development | | |
| Giles Hazan | GPwSI MSK Medicine, Clinical Lead for MSK Medicine High Wealds, Lewes and Havens CCG, Vice President of British Institute of Musculoskeletal Medicine | | |
| Jo Protheroe | Senior Lecturer in General Practice at the Arthritis Research Primary Care Centre, Keele University and GP in NHS Manchester | | |
| Nadine Clark and Emma Hilary | People living with MSK conditions | | |
| Wider engagement | | | |
| David Gilbert | Patient Director for the Sussex MSK Partnership | | |
| Arthritis Support Group, Gateshead with 30+ members | The group has provided ongoing advice and support to the project. | | |
| Dr Iain Goff | Consultant Rheumatologist, Northumbria Healthcare NHS Foundation Trust | | |

Detailed practice information

| | Glenpark | Niddrie | Trinity |
|---------------------------------------|--|--|--|
| Practice population | 9187 | 3366 | 11611 |
| Number of partners | 3 | 3 | 5 (recently undergone merger to become Unity) |
| 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, and COPD 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 |
| MSK conditions focused on | Rheumatoid arthritis Osteoarthritis Osteoporosis Inflammatory spondylopathies Back pain and non- specified Fragility fractures Gout and other crystal arthropathy Fibromyalgia Connective tissue disease | Rheumatoid arthritis Osteoarthritis Osteoporosis Inflammatory spondylopathies Back pain and non- specified Fragility fractures Gout and other crystal arthropathy Fibromyalgia Connective tissue disease | RA only |
| Other points to note | Dr Becky Haines is the lead GP for this | Dr Roland Baumann is a supporting GP for | Dr Stuart Logan is a supporting GP for this |

| | | | |
|--|--|--|---|
| | <p>project. Dr Haines is also a Year of Care trainer following successful completion of the Train the Trainers course in 2015.</p> | <p>this project. Dr Baumann has attended Year of Care care and support planning core training.</p> | <p>project. Dr Logan has attended Year of Care care and support planning core training.</p> |
|--|--|--|---|

Data for Chapter 3: practice register and recalls for phase 1

Shortlist of Read codes for identification for this project

| Individual condition within group | Codes for searches |
|---|------------------------|
| Inflammatory conditions | |
| Rheumatoid arthritis etc | N04% |
| Inflammatory Spondylopathies | N10% |
| Gout & Other Crystal Arthropathy | N02%, C34% |
| 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 |

Initial data from practice searches

Glenpark - practice population 9,000

| | Number of people from search | Number of people marked 'active' | Number currently involved in CSP | Number currently having CSP with 'active' problem | MSK Calculator Gateshead |
|--|------------------------------|----------------------------------|----------------------------------|---|--------------------------|
| Inflammatory conditions | | | | | |
| Rheumatoid arthritis etc | 103 | 91 | 22 | 21 | |
| Inflammatory Spondylopathies | 26 | 13 | 4 | 3 | |
| Gout & Other Crystal Arthropathy | 269 ⁹ | 89 | 89 | 34 | |
| Connective Tissue Disease | 24 | 20 | 5 | 4 | |
| Conditions of musculoskeletal pain | | | | | |
| Osteoarthritis | 1400 (15.3%) | | 434 | | 12.5% |
| Back pain and non-specified | 1899 (21%) | 885 | 667 | 286 | 16.4% |
| Fibromyalgia | 36 | 289 | 9 | 47 | |
| Osteoporosis and fragility fractures | | | | | |
| Osteoporosis | 219 | 186 | 56 | 49 | |
| Fragility fractures | 43 | 27 | 10 | 5 | |
| TOTALS | 4019 | 1410 | 1294 | 401 (31%) | |
| Number of people with two MSK conditions included in searches above | | 186 (13%) | | 49 (12%) | |

⁹ This includes additional 200 gout patients identified in endocrinology code.

Niddrie - practice population 3,400 (please note there are less columns in this table as the practice was unable to identify if problems are *active* from practice system and also no MSK calculator data available)

| | Number of people from search | Number currently involved in CSP |
|--|------------------------------|----------------------------------|
| Inflammatory conditions | | |
| Rheumatoid arthritis etc | 20 | 13 |
| Inflammatory Spondylopathies | 7 | 3 |
| Gout & Other Crystal Arthropathy | 40 | 27 |
| Connective Tissue Disease | 13 | 5 |
| Conditions of musculoskeletal pain | | |
| Osteoarthritis | 214 | 134 |
| Back pain and non-specified | 176 | 66 |
| Fibromyalgia | 10 | 7 |
| Osteoporosis and fragility fractures | | |
| Osteoporosis | 42 | 25 |
| Fragility fractures | 12 | 8 |
| TOTALS | 534 | 288 (54%) |
| Number of people with two MSK conditions included in searches above | 111 (21%) | |

Trinity - practice population 11,500, data from initial use of Read codes identified for 3 groups of MSK conditions

| | Number of people from search | Number currently involved in CSP | MSK calculator Buckinghamshire |
|---|------------------------------|----------------------------------|--------------------------------|
| Inflammatory conditions | | | |
| Rheumatoid arthritis etc | 94 | 94 | |
| Inflammatory Spondylopathies | 77 | | |
| Gout & Other Crystal Arthropathy | 440 | | |
| Connective Tissue Disease | 30 | | |
| Conditions of musculoskeletal pain | | | |
| Osteoarthritis | 2085 (18%) | | 11.5% |
| Back pain and non-specified | 4307 (37%) | | 15.1% |
| Fibromyalgia | 28 | | |
| Osteoporosis and fragility fractures | | | |
| Osteoporosis | 195 | | |
| Fragility fractures | 115 | | |
| TOTALS | 7371 | | |

Data for Chapter 4: inviting people into the care and support planning process - MSK

Glenpark: data for uptake of CSP from birth month recalls in June and July

| | JUNE | JULY |
|--|--|--|
| Total number with MSK and agreed Read codes identified from register search | 99 | 84 |
| Number already having CSP / systematic review because of other conditions | 33 | 26 |
| Total with MSK for new CSP | 66 | 58 |
| EXCLUDED and why | 3 <i>(1 deceased 2 on palliative register)</i> | 5 <i>(All had minor OA coded >20 years ago and no entries since then/ no regular analgesia. Adjusted codes to "Past")</i> |
| 'Interested' after info letter | 20 | 24 |
| 'Not interested' after info letter** | 3 | 0 |
| No response to info letter* | 40 | 29 |
| 'Interested' patients attending CSP appointment | 13 | 14 |
| 'Interested' patients not attending CSP appt and why** | 7 <i>(2 couldn't find suitable appt time/ date and said they would call back 2 became unwell + admitted to hospital in the interim 1 changed mind after further discussion 2 not able to contact them to arrange appointment)</i> | 10 <i>(7 unable to contact them to arrange appointment 1 had op planned "should solve the problem" 2 cancelled as had to be admitted to hospital)</i> |

Glenpark: detailed data on the patients identified from birth month recall search in Jun, July and Aug

Glenpark: Information in the medical record on the non-responders is shown below

| | JUNE BIRTHDAY | JULY BIRTHDAY | AUG BIRTHDAY |
|--|---------------|---------------|--------------|
| Total patients before exclusions | 66 | 58 | 50 |
| Number of patients Read coded as having the following conditions (some patients had more than one code) | | | |
| Rheumatoid | 11 | 7 | 7 |
| Inflammatory Spondyloarthritis | 1 | 0 | 1 |
| Gout | 6 | 6 | 10 |
| Connective Tissue Disorder | 3 | 1 | 0 |
| Osteoarthritis | 47 | 41 | 29 |
| Back Pain | 45 | 28 | 30 |
| Fibromyalgia | 1 | 3 | 1 |
| Osteoporosis/Fragility | 13 | 11 | 14 |
| Number of MSK conditions that each of the 66 patients identified were coded as having | | | |
| 1 MSK condition | 16 | 21 | 28 |
| 2 MSK conditions | 40 | 22 | 20 |
| 3 MSK conditions | 9 | 8 | 2 |
| 4 MSK conditions | 1 | 2 | 0 |
| Number with NO other listed co-morbidities | | | |
| | 26 (39%) | 18 (34%) | 17 (34%) |

| | June | July |
|--|--|--|
| Non-responders who have rheumatoid under regular 2 year care MDT review | 8 | 3 |
| Non-responders who have other conditions/ on medications who will be seen in the year for review* | 18 | 18 |
| Non-responders who have NO other conditions apart from their MSK condition | 10 | 3 |
| Non-responders where notes review has shown inaccurate coding/ no longer active problem | 4 <i>(Minor OA coded many years ago OR OA and joint replacement with no problems since)</i> | 5 <i>(Minor OA coded many years ago OR OA and joint replacement with no problems since)</i> |
| TOTAL | 40 | 29 |

Glenpark: People who declined the invitation

The practice administrator rang 21 of the people who had declined the invitation.

| People with MSK condition | No answer | Didn't know what MSK meant | Not received letter | Will ring back | Not bothered | Interested but forgot | Dates no good | In hospital |
|---------------------------|-----------|----------------------------|---------------------|----------------|--------------|-----------------------|---------------|-------------|
| One condition | 2 | | 2 | | 1 | | | |
| Two conditions | 5 | 3 | 1 | 1 | 2 | 1 | 1 | 1 |
| Three conditions | 1 | | 1 | | | | | |

Glenpark: the MSK conditions of the 21 people who declined (NB some had up to three conditions)

| OA | Osteoporosis Fragility | Lower back pain | RA | Connective tissue disorder | Gout |
|----|------------------------|-----------------|----|----------------------------|------|
| 13 | 6 | 11 | 3 | 1 | 2 |

Niddrie: data on number of CSP conversations/care plans completed

The number of CSP conversations/care plans completed appeared to increase from June onwards. This is likely to be attributed to the simplification and improved wording of the invitation letters.

| | Invitations | Completed care plans |
|-----------|-------------|----------------------|
| March | 1 | |
| April | 1 | 1 |
| May | 9 | |
| June | 36 | 8 |
| July | 39 | 3 |
| August | 21 | 8 |
| September | 14 | 4 |
| October | | 3 |
| November | | 1 |

Data for Chapter 5: preparation for CSP-MSK

Resources for preparation

A range of patient resources (preparation prompts and information sharing) were developed as follows:

- MSK condition information leaflets
- Information sharing (results) letters
- Generic preparation prompt as a covering sheet for all information sharing letters
- Invitation letters appropriate for each MSK condition including self-selection options

The resources are 'condition specific' for gout, joint and muscular pain, osteoporosis and fragility fractures and rheumatoid arthritis.

Data for Chapter 6: using the MSK-HQ and LTC-Q

Samples of the questionnaires are attached below.

MSK-HQ



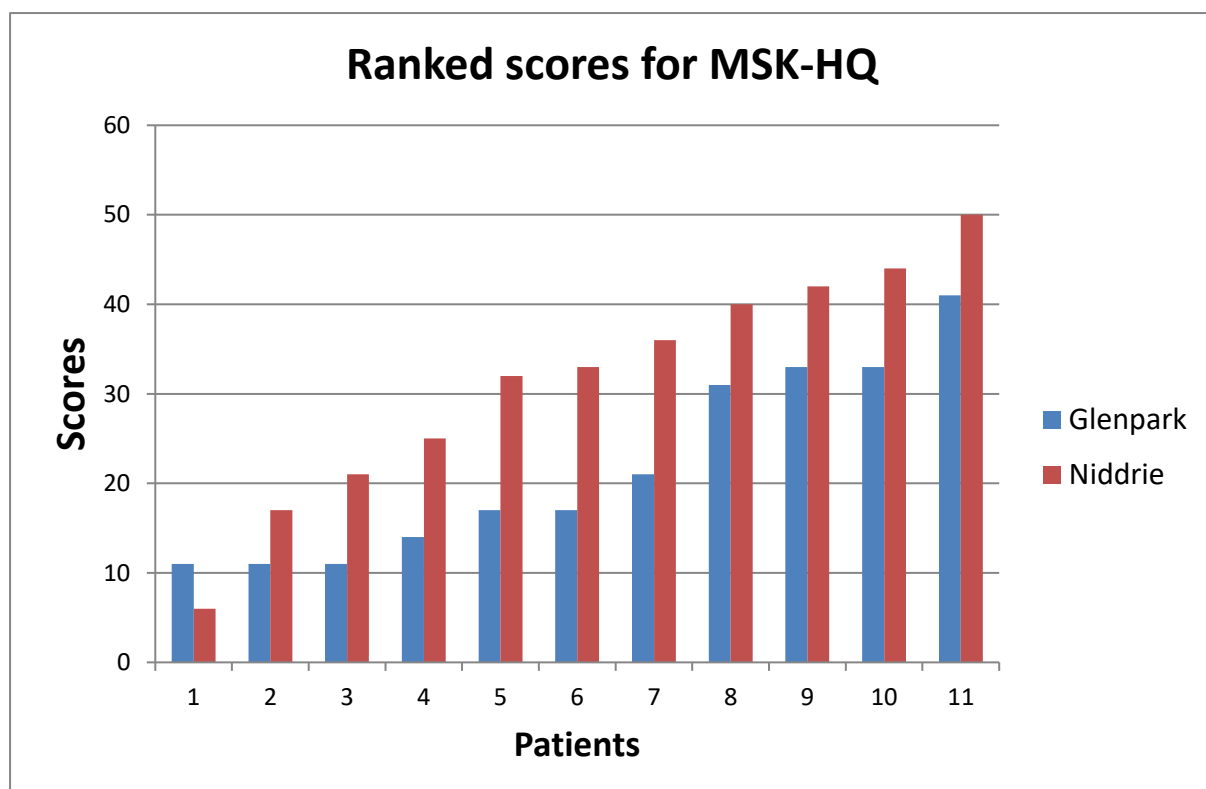
FINAL_ARUK_MSK-H
Q_English_UK.pdf

LTC-Q



LTCQ with scoring -
September 2017.pdf

Distribution of scores of scores from 22 completed MSK-HQs (11 each at Glenpark and Niddrie)
Low scores reflect greater impact of MSK condition on symptoms and function and lower levels of understanding of the condition and confidence to manage it and are shown in the chart below ranked from lowest to highest scores.



Data for Chapter 7: CSP in MSK – the conversation

Staff involved in CSP conversation in the 3 practices

| | GP | Advanced Nurse Practitioner | Practice Nurse | Notes |
|-----------------|---------------------------|-----------------------------|---|---|
| Glenpark | Yes | Yes | | |
| Niddrie | Yes | | | Person sees regular GP to maintain continuity. Only one GP has specific CSP training. |
| Trinity | Yes - a few (if RA alone) | | Yes – the majority (if other comorbidities) | |

Glenpark: Time taken during 25 CSP consecutive MSK conversations (range 12 – 52 minutes)

| Time (in mins) | Number of Conversations |
|----------------|-------------------------|
| 15-19 | 3 |
| 20-24 | 4 |
| 25-29 | 7 |
| 30-34 | 6 |
| 35-39 | 3 |
| 40-44 | 1 |
| 45-49 | 0 |
| 50-54 | 1 |

A5 consultation sheet completed by HCP at end of CSP conversation

This A5 sheet was updated following practice feedback during phase 1. Proposed changes are to be reviewed during the phase 2 kick-off event. Changes include consultation duration and detail on the usefulness of the MSK-HQ.

| | |
|----------------------------|--|
| Conversation number | |
| Main concerns raised | |
| MSK issues discussed | |
| Training issues identified | |
| Outcome and actions | |



Summary of 25 consultations with people with MSK conditions at Glenpark – Becky Haines and Amelia Kerr

Musculoskeletal issues raised at the consultation

| Shoulder pain | Knee pain | Knee and back pain | Knee and neck pain | OA/Pain | Hip pain | Weakness following Surgery | Disc prolapse | RA | Sjogrens | Falls and Knee pain | Osteoporosis |
|---------------|-----------|--------------------|--------------------|---------|----------|----------------------------|---------------|----|----------|---------------------|--------------|
| 1 | 2 | 3 | 1 | 6 | 1 | 1 | 1 | 1 | 1 | 1 | 1 |

Interpretation - osteoarthritis represented the largest group of people who attended the consultation.

Main concerns from people who attended (NB some people had more than one concern)

| Pain | Cramp | Immobility/poor function | Falls concerns | Flare up of symptoms | Medication issues | Low mood/anxiety | Sleep | Weight | Continence | Loneliness | Other |
|------|-------|--------------------------|----------------|----------------------|-------------------|------------------|-------|--------|------------|------------|-------|
| 9 | 1 | 8 | 2 | 2 | 1 | 6 | 1 | 3 | 3 | 1 | 6 |

Interpretation - the main concerns were pain, immobility/ poor function and mood. It could be suggested that reduced function could lead to continence issues which 3 individuals raised. A large number of other issues were raised in the consultation that were not directly linked with MSK issues, concerning a mole, lack of support, dizziness, migraines, side effects of drugs (non MSK related), issues with swallowing and blood pressure. It appears that the invitation enabled the person to raise issues they had not been previously able to address. 6 individuals identified the value of being listened to.

Interventions agreed as a result of the care and support planning conversation

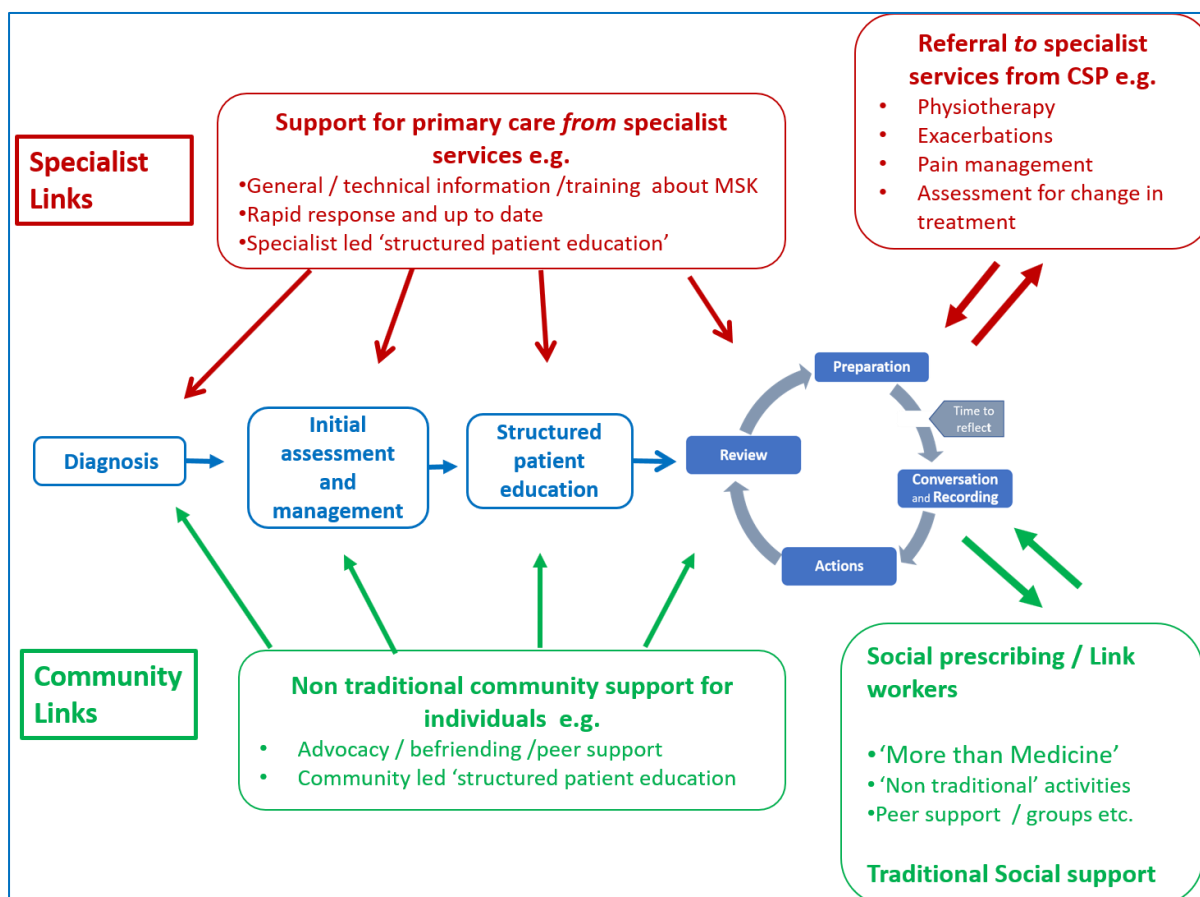
| Falls clinic | Aids | Continence Aids – via District Nurse | Exercise Sheet | Weight support | X ray Or USS Or scan | OT or Physio | Listening | Social prescribing referral | Adult Social Care Referral | Financial support | Talking Therapies | Medication Alteration | No Input | Removal of mole | Discussed Migraine | Referral to Other |
|--------------|------|--------------------------------------|----------------|----------------|----------------------|--------------|-----------|-----------------------------|----------------------------|-------------------|-------------------|-----------------------|----------|-----------------|--------------------|-------------------|
| 1 | 1 | 2 | 2 | 6 | 4 | 6 | 6 | 6 | 1 | 2 | 1 | 8 | 1 | 1 | 1 | 3 |

Interpretation - most common interventions were support with weight management, referral to occupational therapy or physiotherapy for aids adaptation and activity support. Social prescribing, local exercise classes, Thai Chi and support groups, medication alteration (de-prescribing/altering or advice) and 6 individuals expressed importance of being listened to and ability to share their story. Although medication review features, only 5 out of the 8 were linked with the MSK issues, the others were problems with sleeping medication, drug side effects and anti-depressants. It could be suggested that most of the outputs from the conversation were about 'living well' with the MSK condition as opposed to treating symptoms.

Data for Chapter 9: links with wider community - more than medicine and specialist services

Potential links with specialist services in CSP

Practices were given blank templates of the below diagram to complete locally.



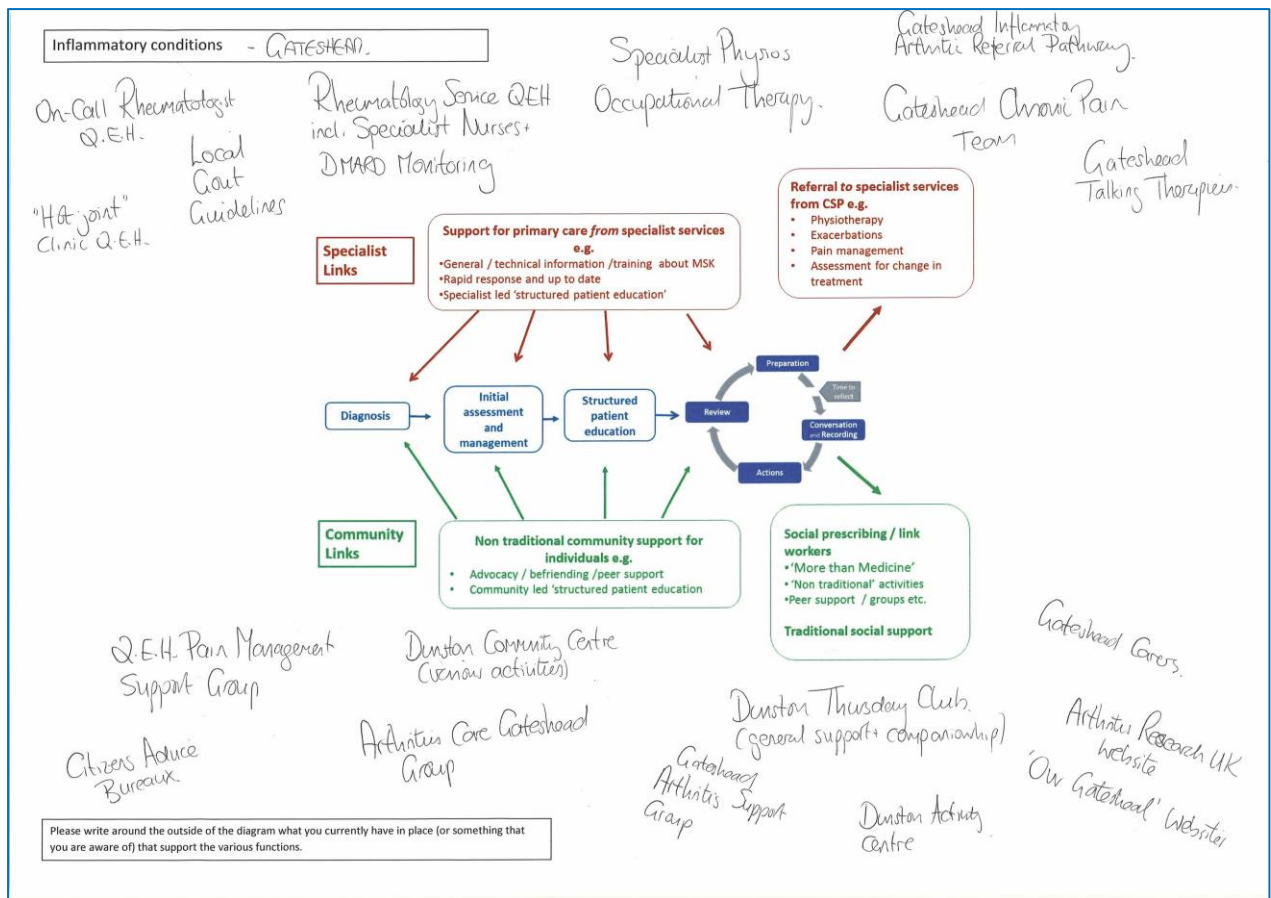
Key

Red – specialist links

Blue – care and support planning process

Green – community links

Early example completed by Glenpark



Local community activities used by phase 1 practices

| Glenpark | Niddrie | Trinity |
|---|---|------------------------------------|
| Ways to Wellness | Thistle Foundation Centre for Wellbeing | 'Use it or lose it' |
| Care Navigator network | ALISS website ('increasingly clunky and out of date') | Live well Stay Well Bucks database |
| 'Our Gateshead' website | Other LA and VCS local initiatives | Active Bucks (activity vouchers) |
| Tai Chi | | Easy change App |
| Dunstan Thursday Club | | Healthy Minds |
| Arthritis Care local group | | Prevention matters |
| Dunstan community centre (various activities) | | EMIS social prescribing module |
| Arthritis research UK website | | |
| Dunstan activity centre | | |
| Gateshead carers | | |
| Citizen's advice bureaux | | |



Data for Chapter 10: evaluation and impact to date

Phase 1 project logic model developed at the start of phase 1

| INPUTS | ACTIVITIES | OUTPUTS | OUTCOMES |
|---|--|---|--|
| <p>PRACTICES AND COMMUNITY</p> <p>Identify x 3 appropriate practices</p> <ul style="list-style-type: none"> • One lead practice • Different demographics • CSP training for some practices members • Payments to practices <p>Define Read codes and search EPRs</p> <p>Community for roll-out/phase 2</p> <p>PROGRAMME</p> <p>ARUK funding</p> <p>PM and clinical lead time</p> <p>Ethics approval</p> <p>Telecon/meeting facilities</p> <p>Service/friends views</p> | <p>PRACTICES AND COMMUNITY</p> <p>‘Set up’ visit - leads</p> <ul style="list-style-type: none"> • Check CSP in place (fidelity) • Compile learning from practices • Practice delivery plan • Identify local pathways into specialist care and community activities <p>Identify all patients who meet the ‘criteria’ for MSK (LTC)</p> <ul style="list-style-type: none"> • Create register <p>Identify community for roll-out</p> <p>PROGRAMME</p> <p>Programme start-up</p> <ul style="list-style-type: none"> • Kick off meeting <p>Regular meetings with ARUK</p> <p>Critical friends</p> <p>Wider professionals/users</p> <p>MSK reference group</p> <p>Testing new skills/knowledge</p> | <p>PRACTICES AND COMMUNITY</p> <p>MSK specific tools for CSP</p> <ul style="list-style-type: none"> • Read codes and registers • Templates for data gathering • Preparation tools <p>Pathways for each conditions which include links to patient to community support and specialists</p> <p>Identify/signpost and link to more than medicine</p> <ul style="list-style-type: none"> • Identify unmet need <p>Professionals with skills in CSP and MSK</p> <p>PROGRAMME</p> <p>Define what CSP looks like for MSK (in context of multimorbidity/single condition)</p> <p>Report for ARUK</p> <p>Evaluation document</p> | <p>PRACTICES AND COMMUNITY</p> <p>Feasibility of CSP in MSK is tested out with capture of methods, tools and learning</p> <p>Including links to specialist care and community support (pathways)</p> <p>Reduced use of resources, inequality and harm</p> <p>Savings/ improved utility of health care resources</p> <ul style="list-style-type: none"> • Prescriptions • Planned vs. unplanned visits <p>Managing MSK better</p> <p>PROGRAMME</p> <p>Guidance for commissioners and primary care teams on how to implement CSP for people living with MSK conditions</p> |

| | | | |
|---|---|--|---|
| <p>EVALUATION Evaluation framework and tools - Angela/Toby</p> <ul style="list-style-type: none"> • What's the role of the MSK-HQ <p>What are the new skills that are needed?</p> <p>What different tools are needed?</p> | <p>EVALUATION Test preparation and CSP tools incl. ARUK MSK-HQ Test out ePROMS Practice level evaluation</p> <ul style="list-style-type: none"> • People with MSK • Practice • System | <p>PEOPLE WITH MSK CONDITIONS People with improved skills/confidence/knowledge supporting self-management</p> <p>Better care experience with a feeling of continuity and being listened to</p> | <p>PEOPLE WITH MSK CONDITIONS People involved in the project with MSK as a single condition or multimorbidity experience CSP</p> <p>They are involved more in their care, feel more in control and considered as a whole rather than as a person with individual, separate conditions</p> |
|---|---|--|---|



Part C: Angela Coulter's practice visit reports

Glenpark



Glenpark visit
6-9-17.docx

Niddrie



Niddrie visit
26-9-17.docx

Trinity



Unity visit
07-11-17.docx