Arthritis Research UK

CARE PLANNING AND MUSCULOSKELETAL HEALTH

ARTHRITIS RESEARCH UK

Arthritis Research UK is the charity dedicated to stopping the devastating impact that arthritis has on people's lives. Everything that we do is focused on taking the pain away and keeping people active. Our remit covers all conditions which affect the joints, bones and muscles including osteoarthritis, rheumatoid arthritis, back pain and osteoporosis. We fund research into the cause, treatment and cure of arthritis, provide information on how to maintain healthy joints and bones and to live well with arthritis. We also champion the cause, influence policy change and work in partnership with others to achieve our aims. We depend on public support and the generosity of our donors to keep doing this vital work.

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CONTENTS

Executive summary 4

1. Introduction 5
   - 1.1 Care planning and musculoskeletal conditions 5
   - 1.2 Report overview 5
2. Care planning 6
   - 2.1 What is care planning? 6
   - 2.2 Legislation and policy 8
3. Arthritis and musculoskeletal conditions 9
   - 3.1 Musculoskeletal conditions and their impact 9
4. Care planning and musculoskeletal conditions 12
   - 4.1 Guidance for care planning in musculoskeletal conditions 12
   - 4.2 Use of care plans by people with musculoskeletal conditions 12
   - 4.3 Care planning pilots involving people with musculoskeletal conditions 14
5. Ensuring care planning supports musculoskeletal health 17
   - 5.1 Overview 17
   - 5.2 Who can benefit? 18
   - 5.3 Healthcare setting 21
   - 5.4 Healthcare professional involvement 21
   - 5.5 Information gathering and sharing 23
   - 5.6 Review frequency 27
   - 5.7 Commissioning services 27
6. Care planning and multimorbidity 30
   - 6.1 Co and multimorbidity 30
   - 6.2 Musculoskeletal conditions as part of multimorbidity 30
   - 6.3 Challenges for care planning in multimorbidity 31
   - 6.4 Care and support planning 33
7. Looking ahead 34
   - 7.1 Recommendations 34
8. Annexes 35
   - 8.1 Workshop programme, participants and extracts 35
   - 8.2 Care planning in legislation and policy 38
   - 8.3 Care planning in NICE Guidance for musculoskeletal conditions 39
   - 8.4 Care planning in ARMA standards of care for musculoskeletal conditions[98] 41
   - 8.5 Methodology for data analysis 42
   - 8.6 References 44
9. Acknowledgements 46

EXECUTIVE SUMMARY

Care planning is an approach that people with long term conditions can use to manage their health and wellbeing. It centres on a collaborative conversation between the person with a long term condition and a healthcare professional, and includes the development of goals and actions which are recorded and shared. The national ambition, set out in the NHS Mandate, is for everyone with a long term condition to be offered a personalised care plan. By taking a holistic approach and empowering people to self–manage, care planning can help to address the growing healthcare challenge of supporting people with long term conditions, including the increasing proportion of people with multimorbidities.

'Seventeen years ago, I experienced a sudden onset of arthritis, which began in the night. I was in excruciating pain and was admitted to hospital, unable to move. Although I began to recover, I later developed fibromyalgia and had to stop work. After years of being a passive patient, I went on a pain management programme. Care planning can give a framework to build on, although it's not 'one size fits all'. ***'Having prepared for the consultation, you can lead the conversation, not the doctor.' – Rob Hemmings***

Arthritis and musculoskeletal conditions affect over 10 million people in the UK today, including people with inflammatory forms such as rheumatoid arthritis, conditions of musculoskeletal pain such as osteoarthritis and back pain, and people with osteoporosis who are at risk of fragility fracture. People with musculoskeletal conditions are part of the wider spectrum of people that can benefit from care planning, and alongside diabetes these conditions can act as an exemplar, illustrating how the approach can be used.

It is important to consider how care planning can be adapted to meet the particular needs of people with musculoskeletal conditions. People with musculoskeletal conditions often access healthcare across several settings, and a wide range of health and allied health professionals contribute to supporting people with these conditions. Care planning has the potential to play an important coordinating role. A lack of biomedical measures to assess musculoskeletal health means that patient–reported outcomes measures can be particularly important to people with musculoskeletal conditions in tracking health and well–being as part of care planning. The frequency of care planning review will vary across the groups of musculoskeletal conditions, and should take into account the needs and preferences of the individual as well as the fluctuating nature of many musculoskeletal conditions.

Only 12% of people with musculoskeletal conditions currently have a care plan. This report highlights the need for care planning to be available to people with musculoskeletal conditions, and for care planning to address the musculoskeletal needs of people with other long term conditions. All healthcare professionals involved in care planning must have appropriate training, including in musculoskeletal core skills. Local provision of services and facilities is needed to enable people to achieve the musculoskeletal health goals agreed during care planning. Looking ahead, there is also a need for ongoing data collection, continued evaluation and shared learning, so that people with musculoskeletal and other long term conditions can achieve the greatest possible benefits from care planning.

1. INTRODUCTION

1.1 Care planning and musculoskeletal conditions

Care planning is an approach that people with long term conditions can find useful in managing their health and wellbeing. National policy states that 'everyone with long term conditions… will be offered a personalised care plan'.[1] Building on the Year of Care programme in diabetes, care planning is becoming more widely implemented across the NHS.

There are over 10 million people living with musculoskeletal conditions in the UK, including many people with long term conditions such as inflammatory forms of arthritis and osteoarthritis.[2] However, only 12% of people with musculoskeletal conditions currently have a care plan (see 4.2). It is important that the benefits of care planning can be fully realised by people with musculoskeletal conditions including rheumatoid arthritis, osteoarthritis and osteoporosis.

1.2 Report overview

This report reviews current policy, clinical guidance, understanding and experience of care planning in relation to people with musculoskeletal conditions. It sets out a series of factors which must be considered to ensure that people with musculoskeletal conditions can benefit from future implementation of care planning.

The report is intended for policy makers, healthcare professionals, academics and individuals interested in long term conditions and supported self–management. This includes people with long term conditions, patient and health professional groups and bodies, research funders, charities, coalition groups and policy leads within NHS England and the Department of Health.

Arthritis Research UK convened a workshop *'Care planning for people with musculoskeletal conditions'* in June 2013 (see 8.1). Care planning experts, clinicians and policy leads joined people with long term conditions to help define the care planning process in relation to musculoskeletal conditions. The discussion and outputs of the workshop informed this report alongside feedback from wider stakeholders. We are grateful to everybody who contributed. National surveys capture data about care planning and new analyses are included in section 4.2.

Arthritis Research UK is committed to ensuring the views of people with musculoskeletal conditions inform our policy work. The experiences of people with musculoskeletal conditions who have tried care planning – and the views of healthcare professionals who have worked with them – are told in their own words.

2. CARE PLANNING

2.1 What is care planning?

Care planning is an approach that people living with long term conditions can use to manage their health and wellbeing. It is an example of the way that self–management support can be systematically put into practice in healthcare services.[i,3]

The central element of care planning is a collaborative, personalised care planning conversation, usually between a person with one or more long term conditions and a healthcare professional (or care and support worker). The conversation brings together information gathered by the healthcare professional and the perspectives of the person with the condition, to allow time for shared goal setting and to develop and record a care plan. Rather than a single appointment, a multi–stage process enables information including test results to be shared in advance so that the person has time to consider their priorities and to consult their family or carers if they wish to.[4]

The stages of the process are:

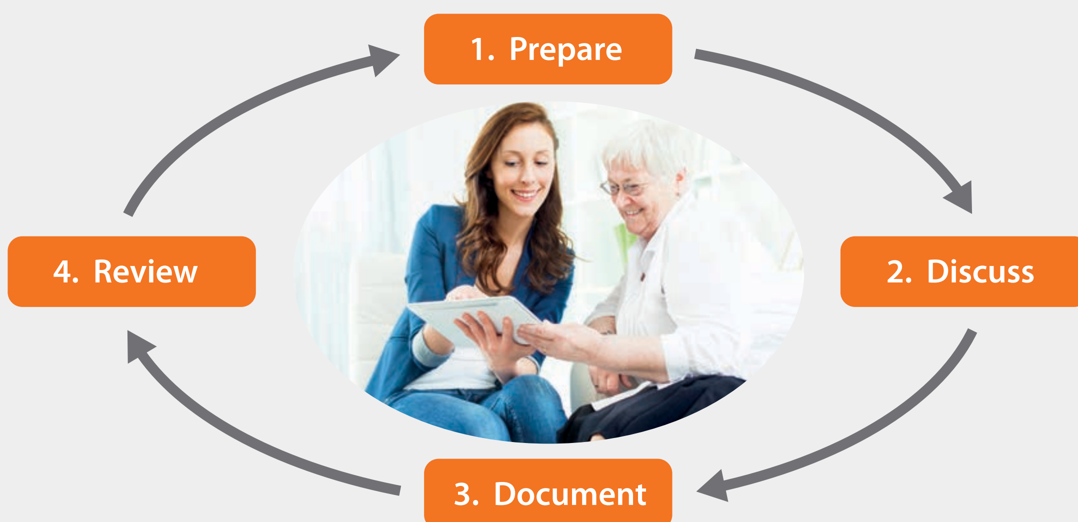
» **Prepare:** information about the person's health and wellbeing is gathered and shared (this can include test results following an initial appointment); the person with the condition considers their health and wellbeing priorities perhaps using a prompt sheet and/or discussion with family members or carers.

» **Discuss:** the care planning discussion enables information and individual priorities to be shared. Goals are set and an action plan is agreed in collaboration to support the person's ongoing health and wellbeing.

» **Document:** A care plan is agreed and shared in an appropriate format.

» **Review:** A review takes place at an interval appropriate for the individual.

Figure 1: Care planning – a cyclical process



The four stages of care planning are linked, the person with the long term condition and a healthcare professional work together through this ongoing process. Step–by–step/practical guides to the care planning process have been published.[5]

i Self–management is an individual's ability to manage the symptoms, treatment and physical and psychological consequences and lifestyle changes inherent in living with a long term condition. Self–management support is a concept that facilitates self–management and results from a person with a long term condition working in partnership with their clinician.

The concept of care planning has evolved over time. The use of care plans as written documents goes back to the early 1990s, when they were developed for people accessing community care services. Since the 1990s care plans have also been used to record the healthcare needs of people with mental health conditions.[6]

From 2007–10 the Year of Care programme piloted care planning within the NHS. This large scale feasibility study defined care planning in a structured way and demonstrated how it could be used by people with diabetes and some other long term conditions.[7] As a result of this work, care planning has become recognised as an ongoing process of collaboration between an individual and a healthcare professional, rather than just the simple documenting of a person's needs in a plan. The Year of Care programme found that five elements are needed to put care planning into practice in healthcare services. These are incorporated into the 'house of care' model.

Figure 2: The house of care

The house of care is a representation of the five elements that need to be in place to deliver person–centred coordinated care through care planning.[8]

The care planning conversation is at the centre.

There is still variation in understanding and use of the terms 'care plans' and 'care planning'. Some people have a written care plan but their experience of care planning differs from the collaborative process developed within the Year of Care programme. Other people aim for health and wellbeing goals which they have developed and agreed with a healthcare professional but don't think of this as care planning.

Increasingly, the use of care planning based on the Year of Care approach is being extended to people with a range of long term conditions and in wider social care settings. This is becoming known as care and support planning (see 6.4).

Figure 3: Evolving definitions of care planning

- 'Care planning is a process which offers people active involvement in deciding, agreeing and owning how their diabetes will be managed. It is underpinned by the principles of patient–centeredness and partnership working… It is an ongoing process of two–way communication, negotiation and joint decision–making in which both the person with diabetes and the healthcare professional make an equal contribution to the consultation.' *Year of Care programme (2006)*.[9]
- Care planning is 'a particular example of support for self–management (SSM) for people with long–term conditions (LTCs)...the regular and repeated structured and proactive process that takes place between the person with an LTC and the health services, based on a collaborative interaction… It may include coordination of care components as well as SSM and will integrate the demands of more than one condition.' *Royal College of General Practitioners (2011)*.[10]
- 'Care and support planning is about someone who needs support from health and/or social care over time, working together with a care and support partner. You should be able to talk about what matters to you and what you want to do or achieve. Together you should work out the best treatment, the right care and support and the actions you can take yourself to help you get there. It becomes a normal part of how you work with the professionals and/or supports you are in contact with.' *National Voices (2014)*.[11]

2.2 Legislation and policy

Care planning is included in both national health and social care policy (see 8.2). The revised mandate to NHS England states that by 2015 'everyone with long term conditions, including people with mental health problems will be offered a personalised care plan that reflects their preferences and agreed decisions.'[12] The General Medical Services contract states that from April 2014, all patients aged 75 and over must have a named GP who will 'work with relevant associated health and social care professionals to deliver a multi–disciplinary care package that meets the needs of the patient.'[13]

The Care Act (2014) introduced care and support plans into national legislation. This social care legislation requires local authorities to involve people in the development of their care and support plan, and to review the plan at the request of the adult involved or their carer.[14]

3. ARTHRITIS AND MUSCULOSKELETAL CONDITIONS

3.1 Musculoskeletal conditions and their impact

Arthritis and musculoskeletal conditions are disorders of the joints, bones and muscles – including back pain – along with rarer systemic autoimmune diseases such as lupus.[15] Together, these conditions affect around 10 million people across the UK and account for the fourth largest NHS programme budget spend in England.[16] Arthritis is the biggest cause of pain and disability in the UK, and each year around 20% of the general population consult a GP about a musculoskeletal condition.[17]

There are three broad groups of musculoskeletal condition:[18]

» The first group is made up of inflammatory conditions such as rheumatoid arthritis. In these conditions the immune system attacks and destroys the joints and sometimes the internal organs. These conditions require specialist care from rheumatologists using drug treatments to suppress the immune system.

» The second group includes conditions of musculoskeletal pain such as osteoarthritis and back pain. In osteoarthritis there is painful wear and degeneration of joints. These conditions are normally treated by GPs in primary care, affect large numbers of people and management usually involves physical activity and pain management. Severe cases of osteoarthritis can result in the need for joint replacement, which can relieve pain and give people back their mobility.

» The third group includes osteoporosis and fragility fractures. Osteoporosis is a painless condition of bone weakening. Fragility fractures occur when frail or weak bones (often caused by osteoporosis) break, often after a trip or fall from a standing height. Fragility fractures affect large numbers of people causing pain and disability. Treatment of people at risk of fragility fracture usually takes place in primary care, and can include bone strengthening medication. Bone fractures can require surgical treatment in hospital.[ii]

Many musculoskeletal conditions including rheumatoid arthritis and osteoarthritis are long term conditions. These conditions can be treated but not yet cured, so people may have the conditions for many years, even decades. People with musculoskeletal conditions have fluctuation in their symptoms with 'flares' (periods of severe symptoms) between periods of mild symptoms. Some musculoskeletal conditions, including forms of back pain and gout (the most common type of inflammatory arthritis) can be effectively treated or can self–resolve so that in–between recurrent periods of disease the person is free of symptoms. Care planning can be used to support self–management of musculoskeletal conditions with fluctuating symptoms, as well as helping to prevent the recurrence of some forms of musculoskeletal conditions.

There is an opportunity for care planning to be used by people with a range of different musculoskeletal conditions, including rheumatoid arthritis, osteoarthritis, osteoporosis, fibromyalgia[19] and gout. The process should be adapted to suit the person involved. Factors including the healthcare professionals involved, the location of the discussion and the review frequency will vary between individuals as well as across the three groups.

ii Falls are more likely in people with poor musculoskeletal health, including in people with weak muscles, stiff joints and reduced coordination. Older people may not survive the trauma of a major fracture.

Figure 4: Three groups of musculoskeletal conditions

Group	1. Inflammatory conditions	2. Conditions of musculoskeletal pain	3. Osteoporosis and fragility fractures
Example	Rheumatoid arthritis	Osteoarthritis	Fracture after a fall from a standing height.[iii]
Age	Any	More common with rising age.	Mainly affects older people.
Progression	Often rapid onset.	Gradual onset.	Osteoporosis is a gradual weakening of bone; Fragility fractures are sudden discrete events.
Prevalence	Common (e.g. around 400,000 adults in the UK have rheumatoid arthritis.[20])	Very common (e.g. 8.75 million people in the UK have sought treatment for osteoarthritis.[21])	Common (e.g. around 89,000 hip fragility fractures occur each year in the UK.[22])
Symptoms	Common musculoskeletal symptoms include pain, joint stiffness and limitation of movement. Symptoms often fluctuate in severity over time.		Osteoporosis itself is painless. Fragility fractures are painful and disabling.
Extent of disease	Can affect any part of the body including skin, eyes and internal organs.	Affects the joints, spine and pain system.	Hip, wrist and spinal bones are the most common sites of fractures.
Main treatment location	Urgent specialist treatment is needed, and usually provided in hospital outpatients.	Primary care for most people; joint replacement requires hospital admission.	Primary care for prevention; hospital for treatment of fractures.
Interventions	A range of drugs and support.	Physical activity, pain management. For severe cases joint replacement may be necessary.	Bone strengthening drugs and fracture liaison services reduce future fracture risk; Fractures may require surgery.
Modifiable risk factors (non–modifiable risk factors include age, sex and genetics)	Smoking	Injury, obesity, physical activity.	Smoking, alcohol intake, poor nutrition including insufficient vitamin D, physical activity.

iii Osteoporosis is a condition of bone weakening which is itself painless. Fragility fractures caused by osteoporosis happen when frail bones break causing pain and disability. More generally, bone fractures can be due to trauma or injury. This report focuses on fractures that are due to an underlying musculoskeletal condition.

12% of people with a musculoskeletal condition say they have a care plan

By 2015… everyone with long–term conditions …. will be offered a personalised care plan that reflects their preferences and agreed decisions[24]

18% of people with osteoarthritis say they have a care plan[23]

4. CARE PLANNING AND MUSCULOSKELETAL CONDITIONS

4.1 Guidance for care planning in musculoskeletal conditions

All National Institute for Health and Care Excellence (NICE) clinical guidelines emphasise the importance of patient–centred care, which takes into account people's needs and preferences and enables them to make informed decisions in partnership with healthcare professionals. These principles are at the centre of the care planning approach.

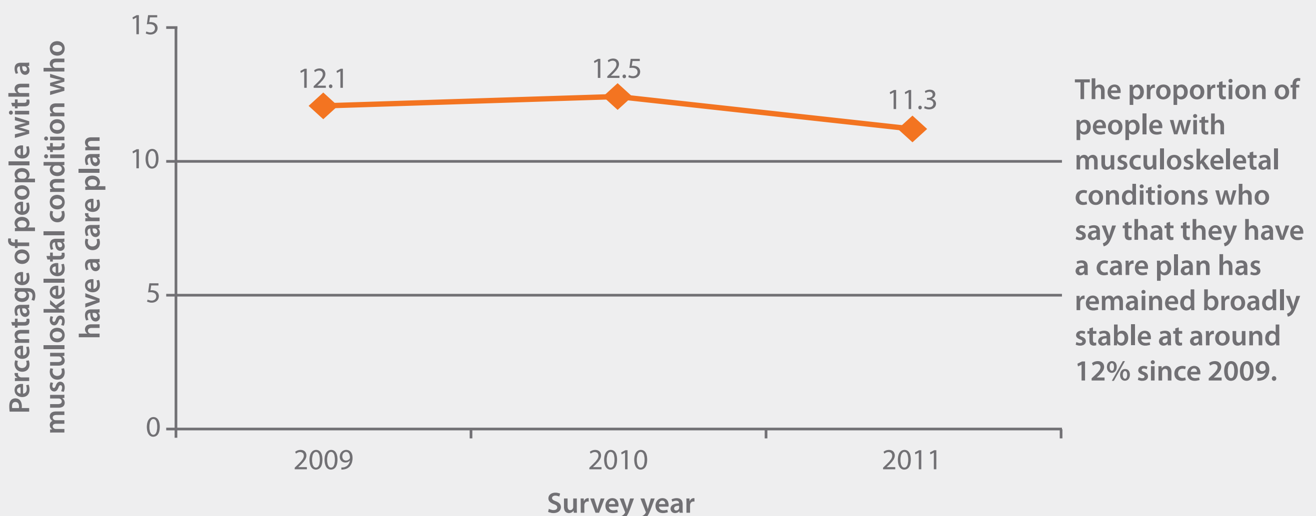
NICE clinical guidelines for musculoskeletal conditions refer to aspects of the care planning approach, although they do not specifically use the term care planning. The clinical guideline for osteoarthritis recommends that healthcare professionals should 'agree a plan with the person (and their family members or carers) for managing their osteoarthritis' and 'ensure that information sharing is an ongoing, integral part of the management plan'. It recommends that 'individualised self–management strategies' should be agreed and a review offered at an agreed time.[25] Clinical guidelines for rheumatoid arthritis, psoriasis and low back pain, and the NICE quality standard for rheumatoid arthritis, also include elements of care planning (see 8.3).

Standards of care produced by the Arthritis and Musculoskeletal Alliance (ARMA) set out optimal healthcare for nine musculoskeletal conditions.[26] Seven of these include the need for supported self–management approaches, and those for connective tissue disease, inflammatory arthritis, juvenile inflammatory arthritis, musculoskeletal foot health, osteoarthritis and regional musculoskeletal pain identify the need for individualised care plans (see 8.4).

4.2 Use of care plans by people with musculoskeletal conditions

Around 12% of people with a musculoskeletal condition say they have a written care plan. Surveys of people with specific types of musculoskeletal condition also indicate that only a minority have a care plan.

Figure 5: Care plan use by people with musculoskeletal conditions



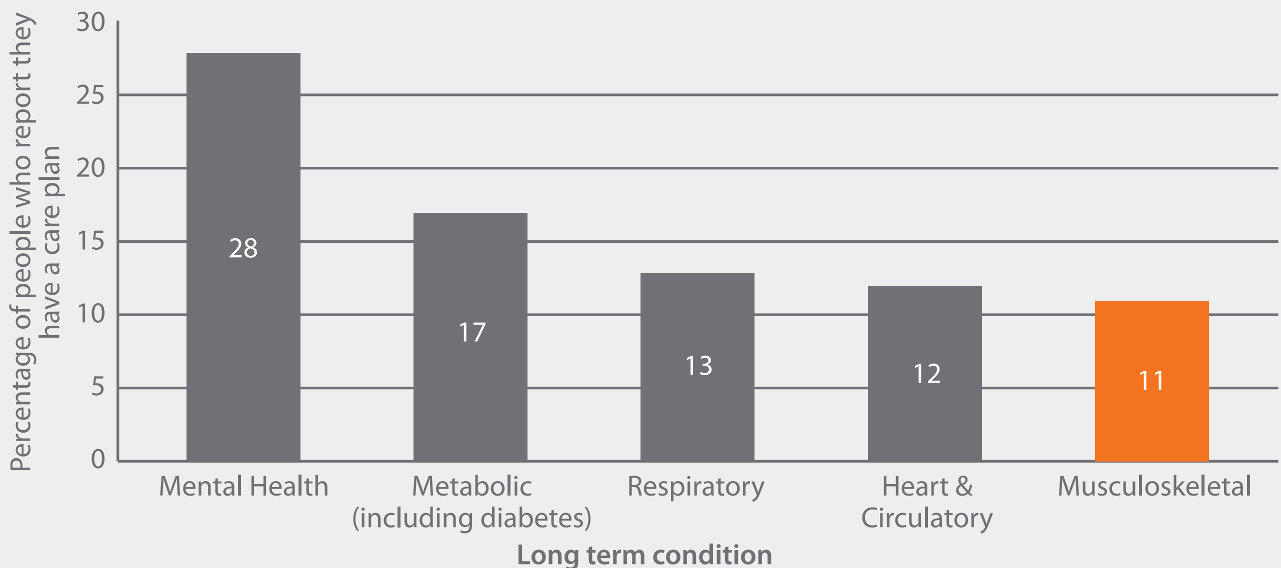
Data source: Health Survey for England. For methods see 8.5.

Figure 6 : Use of care plans by people with musculoskeletal conditions

Percentage of respondents	Data source (Date)	Definitions
11.3%	Health Survey for England (2011).[See 8.5]	People with a musculoskeletal condition (arthritis, rheumatism or fibromyalgia) who say they have a written care plan
5.5%	General Practice Patient Survey (GPPS) (2013).[See 8.5]	People with arthritis or a long–term joint problem who say that they have a written care plan
4.7%	General Practice Patient Survey (GPPS) (2013).[See 8.5]	People with a long–term back problem who say that they have a written care plan
20%	Arthritis Care Survey (2010).[27]	People with rheumatoid arthritis who say they have a personal care plan
48%	NRAS survey (2010).[28]	Consultant rheumatologists who say their patients have access to a personalised care and management plan
18%	Arthritis Care Survey (2012).[29]	People with osteoarthritis who say they have an agreed care plan

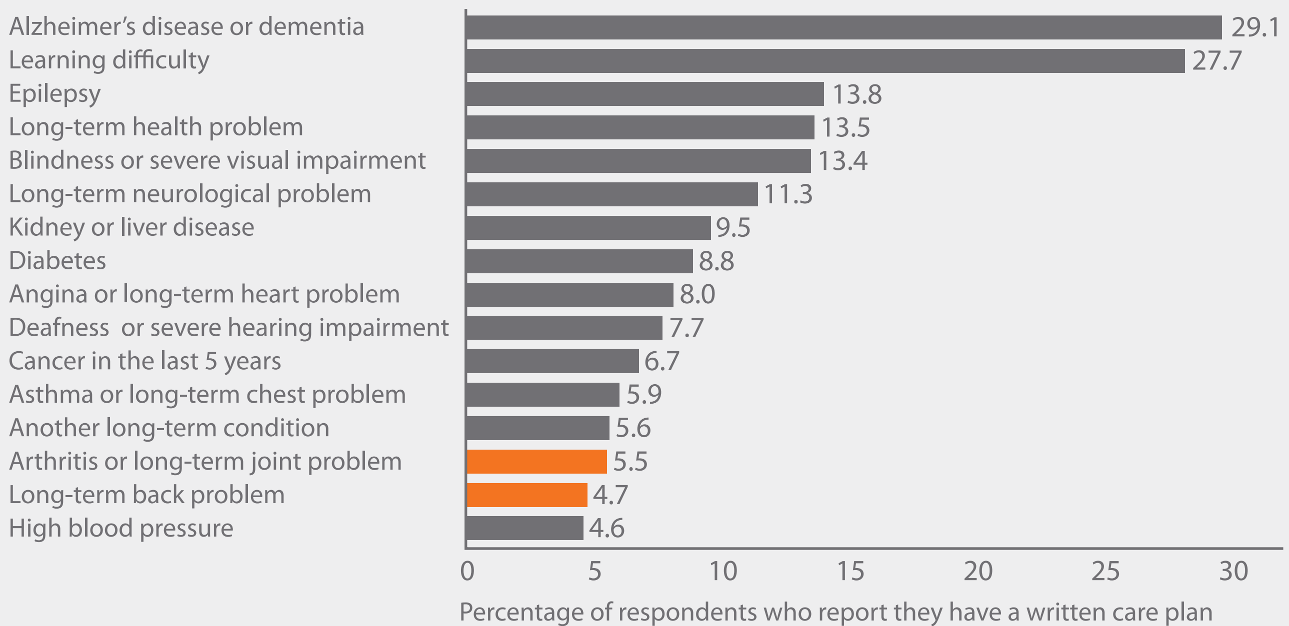
The proportion of people with musculoskeletal conditions who say that they have a written care plan is similar to that among people with cardiovascular conditions, respiratory conditions such as chronic obstructive pulmonary disease, slightly lower than people with metabolic disease including diabetes, and much lower than people with mental health conditions.

Figure 7a: Care plan possession by people with long term conditions



Data source: Health Survey for England (2011). For methods see 8.5.

Figure 7b: Care plan possession by people with long term conditions



Data source: General Practice Patient Survey (2013). For methods see 8.5.

4.3 Care planning pilots involving people with musculoskeletal conditions

Supported self–management approaches have been shown to benefit people with musculoskeletal conditions, including those with chronic pain. Care planning, however, has not yet been systematically trialled in people with musculoskeletal conditions.

Figure 8: Other supported–self management approaches in musculoskeletal conditions

- **Self–management support: Calderdale and Huddersfield NHS Foundation Trust**
  A five year pilot within the Health Foundation's Co–creating Health programme tested the benefits of a self–management programme in people with musculoskeletal pain. The programme included joint care, pacing, weight and diet monitoring, and techniques to reduce stiffness, manage pain, set goals, and maintain motivation. People who took part were found to have improved confidence in managing their condition, less medication use and fewer encounters with health professionals.[30,31]

- **Shared decision–making: Your Health – Your Decision**
  Musculoskeletal health was one of the clinical areas chosen to implement shared–decision making in routine NHS care within the national Shared Decision Making Programme in 2012. Within the AQuA programme, the goal of 80% of patients in musculoskeletal clinical pathways being fully involved in their care (through patient decision aids, Shared Decision Making or the 'Ask 3 Questions' approach) was met.[32]

Interviews with people with osteoarthritis and rheumatoid arthritis from one of the Year of Care pilots highlight the interdependency between musculoskeletal and overall health and the need for care planning to take musculoskeletal conditions into account.

Jabida's view on care planning

Jabida's house is busy; her days are filled with children, grandchildren, school runs and cooking, often leaving her worn out. She has osteoarthritis in both knees, and problems with a knee replacement operation have made the links between her arthritis and her overall health clear. Nerve damage has left her knee extremely hot and swollen, particularly at night, with very little movement. Until she has a further operation, Jabida can't walk without crutches, has to sit more and is putting on weight. This is affecting her ability to manage her overall health – she has had diabetes for six years, and also has high blood pressure, high cholesterol and an irritable bowel: *'I forget half the things I take medication for, when you take that much medication you forget.'*

Jabida always goes to the GP about her health, except for eye tests at the hospital. She has been using care planning with a diabetes nurse for around three years. Results including her blood sugar levels, urine analysis and blood pressure are recorded and she keeps a copy at home:' …*it's all in the blue folder and then if you need to look at anything it's all there.'* She finds the care plan helpful: 'when the forms come up and all the test results are there, and …*it tells me I'm doing things right …that's peace of mind. I come out of there knowing, well, something's ticking right.'*

Although her arthritis isn't currently recorded on her plan, the opportunity is there – the nurse usually asks about Jabida's pain and pain medication, and looks at the movement in her knees. Jabida feels that, especially for people who are not mobile, it is better when tests and health care is co–ordinated and fewer appointments are needed. *'You need it all under one roof, you need it all in one place, and then you know where to go when things aren't right, you've just got the one point where you can go and sort everything out. That must be better for everybody to have that.'*

Terry's thoughts on care planning

Terry, 74 enjoys rock and roll and walking along the seafront with his daughter. He takes each day as it comes and thinks it's important to get out and enjoy yourself. He has had both his knees replaced due to osteoarthritis. *'All I know is that if they didn't do my knees I would probably have ended up in a wheelchair. It was that bad… I had to practically crawl up the stairs.'* Terry also developed rheumatoid arthritis which led to him having to retire from his job as a school caretaker – it became so painful he couldn't bear even to shake hands.

Since his early 60s, Terry's health has also been affected by type 2 diabetes, high blood pressure and eye problems. He has a care planning record from his diabetes nurse, which enables him to track his weight, blood pressure and cholesterol and other aspects: *'The nurse writes a record for me to bring home and she has one for herself …she always goes through it with me and then gives me a copy to take home to read, or whatever I want to do,… or put it away for next time. You can compare then, can't you.'*

Terry goes to several hospitals for check–ups, including a rheumatology clinic at the local hospital, and a specialist eye hospital. He has blood tests at his general practice to monitor the medication for his rheumatoid arthritis. He uses his GP's support to manage different aspects of his health. His GP is in contact with the different specialists, and Terry asks him if he wants to know anything.

One thing that helps is a phone based system: *'There's a new system… You talk to the doctor, if you want to make an appointment you go through your doctor now, not through reception… I like it that way. Sometimes it saves you going to the surgery. You can chat to him, you can tell him what you're feeling, or anything like that. It helps doesn't it… if he's worried, he'll tell you to come…'*

Building on the initial Year of Care programme, a one year pilot in ten GP practices in NHS North East used the Year of Care approach in a wider range of long–term conditions. This pilot included people on disease modifying drugs for arthritis, as well as people with chronic obstructive pulmonary disease (COPD), learning difficulties, and people with multimorbidities. At the end of the study only one practice remained sceptical about the advantages of care planning beyond diabetes and all the others were actively implementing change.[33]

5. ENSURING CARE PLANNING SUPPORTS MUSCULOSKELETAL HEALTH

5.1 Overview

This table summarises the main aspects of the care planning process used by people with musculoskeletal conditions, including a guide to indicate those most likely to benefit.

Group	1. Inflammatory conditions	2. Conditions of musculoskeletal pain	3. Osteoporosis and fragility fractures
Examples	Rheumatoid arthritis, Ankylosing spondylitis	Osteoarthritis, Back pain[iv]	Osteoporosis, fragility fractures
Most likely to benefit	All[v]	People who have ongoing need for support to manage their symptoms, treatment, physical or psychological consequences of their condition. This includes: people who attend healthcare services three or more times a year; people who attend pain clinics	People at high risk of fracture who need ongoing support to manage their treatment, symptoms, physical or psychological consequences of their condition. This includes people who have experienced a fragility fracture[vi]
Less likely to benefit	People who do not wish to self–manage, or engage with the care planning process		
Point of initiating care planning	At the point of diagnosis	From the point at which people agree they need ongoing support to manage their condition	From the point at which high risk is established
Indicators which can to help identify people likely to benefit	Indicators of severe disease e.g. antibody responses;[vii] Multimorbidity	Symptoms that can only be managed by regular medication; A&E attendance due to this condition; Multimorbidity	A fragility fracture; Family history of fragility fracture or osteoporosis; Multimorbidity
Healthcare professionals (HCPs) to gather information to inform care planning may include:	Rheumatology specialist; Specialist nurse; General Practice/ Primary Care nurse; Physiotherapist	GP; General Practice/ Primary Care nurse; Physiotherapist	GP; General Practice/ Primary Care nurse; Fracture Liaison Service specialist nurse[viii]
Input needed from:	The person with the condition – and as appropriate their family or carers		
Input may also be needed from:	Physiotherapist; Occupational therapist; Podiatrist; Pain specialist; Psychologist; Pharmacist; (Ortho)geriatrician; Radiologist; Acupuncturist; Social care professionals[ix]		
HCPs to support care planning	GP or specialist nurse[x]	GP[x]	
Healthcare settings	Specialist settings and general practice to link up	General practice or pain clinic[xi]	General practice
Review frequency[xii]	Annual	Every 1–3 years	Every 1–3 years

Footnotes for table on page 17

iv There is a broad spectrum of severity of symptoms experienced by people with conditions of musculoskeletal pain.

v A small proportion of people diagnosed with forms of inflammatory arthritis may move into treatment–free remission and so be unlikely to need/or significantly benefit from care planning.

vi Care planning may also benefit people who fall regularly. There are multiple reasons that people fall; some falls are related to aspects of musculoskeletal health including bone and muscle strength, others are due to wider health issues including vision and balance. Multi–factorial assessment should be provided for people who fall regularly.

vii Presence of auto–antibodies (including rheumatoid factor (RF) and anti–citrullinated protein antibodies,(ACPA) are used as biomarkers indicating more severe forms of inflammatory arthritis.

viii Fracture liaison services (FLS) may gather information before referring people to general practice for secondary management of osteoporosis/fragility fracture.

ix For forms of inflammatory arthritis input may be needed from a gastroenterologist, ophthalmologist, dermatologist, or cardiologist; for people with multi–morbidity, input may be needed from healthcare professional relevant to comorbidities. A multi–disciplinary team (MDT) approach can be beneficial.

x There is scope for others to take the healthcare professional role in the care planning process, particularly rheumatology specialist nurses, general practice nurses, specialist physiotherapists, primary care professionals. With appropriate training, members of care home support, social or community workers may also take on this role.

xi Where these exist locally.

xii Review frequency is suggested, and should be adjusted in response to individual preferences and fluctuations in the condition. For newly diagnosed inflammatory arthritis (Group 1), monthly review may be needed. Case management in group 3 may be less frequent (every 5 years). An annual offer of a review can be a useful support.

5.2 Who can benefit?

Demonstrating health and economic outcomes of interventions which aim to make healthcare more patient–centred is complex.[34] However, evaluation of the Year of Care Programme found that improvement in the health outcomes of diabetics could be seen after 2–3 cycles of care planning, and practice productivity improved.[35]

Care planning can have a different role in a person's overall healthcare depending on their needs and preferences. For a person with musculoskeletal symptoms that are well–controlled and a strong ability to self–manage, care planning may act as the main treatment intervention and contact with healthcare services. For people with lower self–management ability or with complex conditions, care planning can be one aspect of wider treatment and healthcare service contact and have more of a coordinating function. Care planning can also be used by people caring for those with musculoskeletal conditions.

[Care planning] … 'allows patients to set priorities even if these are at odds with 'medical goals' … this can allow more collaborative and realistic goal setting.' [36]

Care planning and inflammatory forms of arthritis

Care planning is appropriate for people with inflammatory forms of arthritis, such as rheumatoid arthritis, from the point of diagnosis. People with these conditions typically require ongoing specialist contact from a multidisciplinary team to manage their condition. Indicators which can identify people particularly likely to benefit from care planning include:

- the use of treatments such as biologics
- biomarkers indicating severe forms of disease[xiii]
- high use of social care services
- multimorbidity
- loss of work/inability to work due to poor control of severe disease symptoms

A sub–group of people diagnosed with inflammatory arthritis achieve 'remission' and are able to self–manage their conditions effectively with minimal support. They may still benefit from care planning but a longer review frequency could be appropriate.

Care planning and musculoskeletal pain

People with conditions of musculoskeletal pain, including osteoarthritis and back pain, form a broad spectrum. Symptoms can range from mild pain and stiffness to severe pain, swelling and inflammation that prevent everyday activities. The majority of people with conditions of musculoskeletal pain seek treatment in primary care. This can be intermittent contact over years depending on symptom severity and on whether symptoms are ongoing or self–resolving. Care planning is an appropriate approach for people with conditions of musculoskeletal pain who have moderate or severe symptoms, including those who regularly attend healthcare services. Factors which identify people most likely to benefit include:

- pain clinic attendance
- symptoms that can only be managed by regular medication
- accident and emergency attendance
- multimorbidity

Care planning may not benefit people with musculoskeletal pain who can self–manage mild symptoms effectively without structured support.

> *'…for people with osteoarthritis there are strong links between finding their treatment effective and feeling that they are given the time they need with their medical practitioner … People who have a care plan agreed, who discuss self–management with their doctor and who set goals are more likely to see their treatment as effective.'* [37]

Care planning, osteoporosis and fragility fractures

Care planning is appropriate for people with osteoporosis and fragility fracture in two ways. There is an opportunity to identify people with osteoporosis at high risk of fragility fracture in general practice and to use a care planning approach to prevent people experiencing a first fracture. Indicators which can identify people most likely to benefit from include:

- family history of fragility fracture or osteoporosis
- multimorbidity

After a fragility fracture, shared decision making rather than care planning, may initially be the best form of support for self–management to ensure the person is involved in choices around surgery and joint replacement.[xiv,38] However, care planning is an appropriate means of supporting long term recovery following a fall or fragility fracture.

Across all musculoskeletal conditions, the person involved must be willing and able to engage in the care planning process for it to be effective. Care should be taken to ensure that poor health literacy, or a lack of confidence in ability to self–manage do not act as barriers preventing people from using care planning.

> *'I think for some patients it is a really useful tool to bring up areas for discussion and agree a plan. It's not for everyone though – some patients really don't engage with it.'* [39]

xiv Shared Decision Making (SDM) is a process in which patients are encouraged by their health professional to participate in selecting the most appropriate health treatments or care management options for their individual needs and preferences.

How might people with musculoskeletal conditions use care planning?

Care planning may not be the right approach for everybody, all the time:

Jane is 44 and doesn't want to waste time bothering about her health. Her work, children and finances give her enough to worry about. Her GP said she had osteoarthritis in her right knee, and that exercise and weight loss might help with the pain, and reduce her chance of needing to have it replaced in the future. Jane said she just didn't have time for it, and didn't see the point in thinking about what she could do to be healthier if she would need a replacement in the end anyway. She just wanted some pills for the pain. Her GP said to go back if she changed her mind or wanted more information, but she didn't think she would.

5.3 Healthcare setting

Group	1. Inflammatory conditions	2. Conditions of musculoskeletal pain	3. Osteoporosis and fragility fractures
Healthcare settings (where care planning takes place)	Specialist settings and general practice to link up	General practice or pain clinic	General practice

People with musculoskeletal conditions access services in primary, secondary and community healthcare, and in social care settings. Wherever it takes place, care planning for people with musculoskeletal conditions should enable information gathered across the healthcare services to be incorporated.

People with inflammatory forms of arthritis typically access services in multiple settings including rheumatology outpatients, general practice and physiotherapy centres. Co–ordination of care across settings can be difficult, and a lack of joined up healthcare frustrating for people with inflammatory arthritis. Care planning can help to address this. One approach for people with inflammatory arthritis is for the preparatory stage of care planning to take place in secondary care conducted by (or under the guidance of) a rheumatologist as part of an annual review. Test results are shared with the person involved, together with materials to support them in considering their health and wellbeing priorities. A follow up care planning discussion and development of a care plan would subsequently take place in general practice, involving a GP or a practice nurse.

> *'One big problem is that my hospital is in a different place [to my GP] so my records are on different computer systems – it's a paperchase with lots of information floating about. It's difficult to keep pace with all the bits of paper … with musculoskeletal conditions, unless one particular hospital 'takes ownership of you/your condition' then moving between hospitals is very difficult.'* [40]

People with conditions of musculoskeletal pain have the majority of their treatment in primary care. A care planning approach similar to that in the Year of Care could be used, with an initial nurse–led appointment used to record and share health information, allowing the person time to reflect before the care planning discussion. Care planning could also take place in a pain clinic where these are available. Care planning for people with osteoporosis or at risk of fragility fracture is also likely to be based in general practice. Following a fragility fracture it would be important to ensure information gathered by fracture liaison services is incorporated.

5.4 Healthcare professional involvement

Group	1. Inflammatory conditions	2. Conditions of musculoskeletal pain	3. Osteoporosis and fragility fractures
HCPs to gather information to inform care planning may include:	Rheumatology specialist; Specialist nurse; General Practice/Primary Care nurse; Physiotherapist	GP; General Practice/ Primary Care nurse; Physiotherapist	GP; General Practice/ Primary Care nurse; Fracture Liaison Service Specialist nurse
Input may also be needed from:	Physiotherapist; Occupational therapist; Podiatrist; Pain specialist; Psychologist; Pharmacist; (Ortho)geriatrician; Radiologist; Acupuncturist; Social care professionals		
HCPs to support care planning:	GP or specialist nurse	GP	

An important function of care planning is to bring together the expertise of healthcare professionals who contribute advice to support a person's health and wellbeing. A range of specialists and allied health professionals are involved in the healthcare of people with musculoskeletal conditions. It is important to ensure that the roles of different healthcare professionals in the care planning process are clear. Good communication and clarity of responsibility is vital.

How might people with musculoskeletal conditions use care planning?

Supporting the carer, and integrating health and social care:

Bill is 70 and looks after his wife Julie, who is 68. They wanted to stay living at home after Julie had a stroke last year. The osteoarthritis in Julie's hands means she needs some help to get dressed and sometimes with meals. Bill is not sure Julie really understood when they put together her care plan with the community health worker – but he checks it to make sure he fills Julie's weekly pill organiser correctly, and it has all her appointment details, and contact numbers in case there are problems. It also means he doesn't have to keep explaining Julie's story and remembering the right words – he finds it easier just to hand over the folder so that all the different people they see can read it and get up to speed.

The healthcare professional involved in the care planning discussion should be someone able to consider the person's needs in a holistic manner and would normally be closely involved with them. The preferences of the individual in choosing a person to work with should be taken into account. It may often be their GP, but there is scope for other healthcare professionals to take on this role, particularly rheumatology specialist nurses, physiotherapists and general practice nurses, and appropriately trained members of care home staff and care workers. The ability of nurses and physiotherapists to independently prescribe means that they are increasingly well placed to take on this role.[41]

5.5 Information gathering and sharing

Effective care planning for people with musculoskeletal conditions should be informed by the priorities of the person and by information collated by the healthcare professional. Both should be shared in advance in an appropriate format.

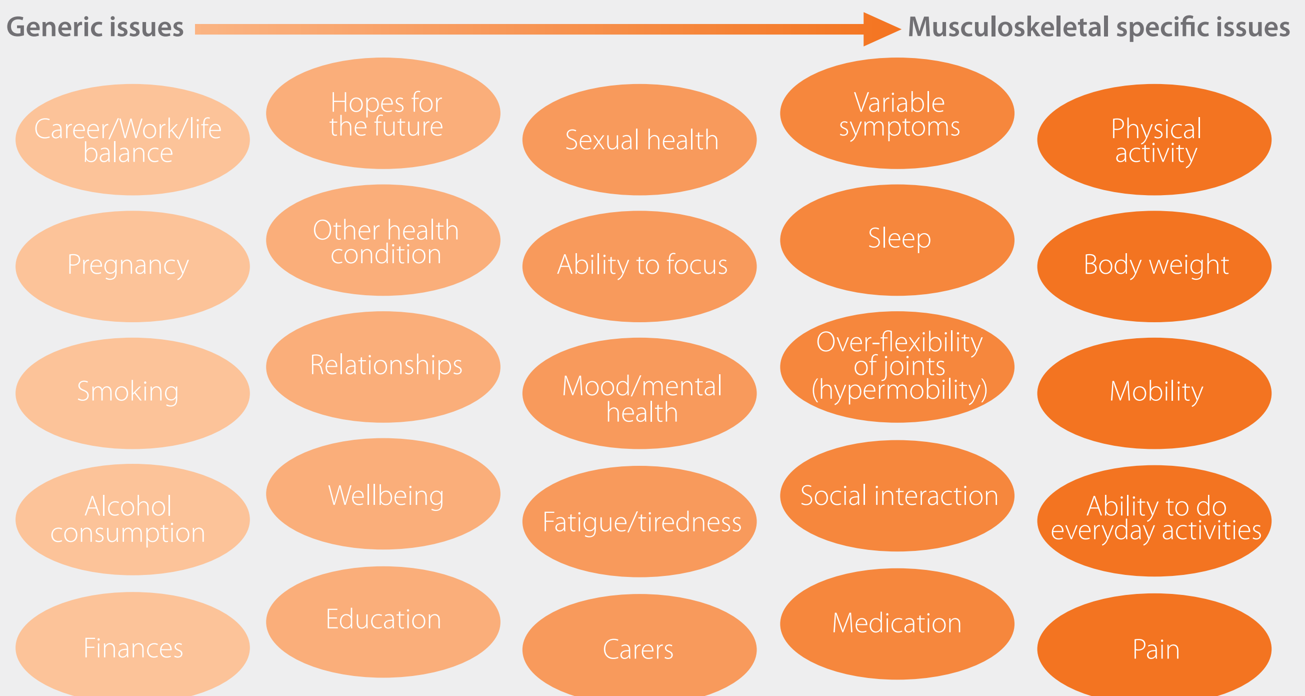
> *'I think that care planning works best when it is considered less as a process and more as an approach by which to work collaboratively with patients – sharing information, understanding priorities and identifying goals to get the best outcomes.'* [42]

Prompt sheets can be helpful in enabling people to identify and discuss their health and wellbeing priorities. Sheets used in the Year of Care programme were tailored towards the main condition of the person involved. For example, in diabetes pilots they included 'monitoring blood glucose' and in chronic obstructive pulmonary disease pilots 'breathless'. However, generic aspects of health (e.g. pregnancy) and wider wellbeing concerns (such as housing or relationships) were also included.

Managing pain and maintaining mobility can be priorities for people with musculoskeletal health conditions. Wellbeing concerns which can be particularly important include social interaction, which can be limited for people with poor musculoskeletal health who are unable to walk or travel easily. People with any long term condition should consider their musculoskeletal health and its impact on their wider wellbeing during care planning.

Everybody has unique health priorities and concerns which vary throughout their life, and prompt sheets can only provide a guide to support people in discussing these. Over time it may be more effective to include prompts which are personalised and chosen by the individual.

Figure 9: What matters most to you about your health and wellbeing?



This table illustrates factors that might be included in a prompt sheet to support people in considering their musculoskeletal health priorities as part of their overall wellbeing.

Figure 10: Examples of measures and information to support care planning for people with musculoskeletal conditions

	1. Inflammatory conditions	2. Conditions of musculoskeletal pain	3. Osteoporosis and fragility fractures
Measures of disease severity	**Disease activity** (e.g. using DAS[xvi] including CRP[xvii] or ESR[xviii] and tender and swollen joint counts; frequency and severity of flares; or BASDAI[xix] (for ankylosing spondylitis)) **Functional ability** (e.g. using HAQ (for rheumatoid arthritis),[xx] RAQoL[xxi] or EQ–5D[xxii]) **Pain assessment** (e.g. using VAS[xxiii]) **Sleep quality**	**Functional ability** (e.g. using TUG,[xxiv, 43] Oxford Hip/Knee scores, DASH,[xxv] the Roland–Morris disability questionnaire,[xxvi] WOMAC or AUSCAN indices,[xxvii] Grip strength, EQ–5D, or waking stiffness and duration) **Pain assessment** (e.g. using VAS) **Sleep quality**	**Assessment of risk of fracture** (e.g. using FRAX,[xxviii] DEXA, QFracture[xxx]) **Functional ability**
Comorbidity	Including hypertension, ischaemic heart disease, osteoporosis and mental health status (e.g. using PHQ[xxxi])	Including mental health status, (e.g. using PHQ)	Including mental health status, (e.g. using PHQ) and vision
Activities of daily living	**Ability to work; Support network; Carer; Relationships and social interaction; Leisure activities; Environment (e.g. care home)**		
Lifestyle risk factors	**Smoking**	**Level of physical activity; obesity**	**Smoking, Diet** (including Vitamin D, calcium and alcohol intake) **Level of physical activity**
Health beliefs	**Attitude to exercise; Concerns, expectations and knowledge of condition** (e.g. using PAM[xxxii,44])		

This table illustrates some of the measures and factors which can be gathered by healthcare professionals to inform care planning discussions for people with musculoskeletal conditions. It is not comprehensive, but is taken from measures suggested at the stakeholder workshop and factors included in NICE clinical guidelines (rheumatoid arthritis and osteoarthritis) and the jointly produced clinical guideline for osteoporosis.[45] Measures of overall health (e.g. height, weight, blood pressure) as well as factors such as current medication would also be used in informing care planning discussions.

Footnotes for table on page 24

xv For further information see http://www.arthritisresearchuk.org/policy–and–public–affairs/policy–priorities–and–projects/musculosketal–health–services/patient–reported–outcome–measures.aspx#sthash.E1oDhXI2.dpuf

xvi The disease activity score (DAS) is used to measure disease activity in rheumatoid arthritis. Accessed on–line at http://www.das–score.nl/

xvii C–reactive protein (CRP) level in the blood rises in response to inflammation and can be used to measure disease activity.

xviii Erythrocyte sedimentation rate (ESR) is a non–specific measure of inflammation which can be used to measure disease activity.

xix The Bath Ankylosing Spondylitis Disease Activity Index (BASDAI) is used to measure and evaluate disease activity in Ankylosing Spondylitis. Accessed on–line at http://basdai.com/

xx The health assessment questionnaire (HAQ) is a self–reported measure of functional status (disability) used to measure outcomes in rheumatoid arthritis, osteoarthritis and other forms of rheumatic disease. Accessed on–line at http://aramis.stanford.edu/HAQ.html

xxi The Rheumatoid Arthritis Quality of Life (RAQoL) questionnaire can be accessed on–line at http://rheumatology.oxfordjournals.org/content/36/8/878.full.pdf+html

xxii The EQ–5D health questionnaire provides a descriptive profile and index value for health status. Accessed on–line at http://www.euroqol.org

xxiii The visual analogue scale (VAS) score is the most widely validated pain score in clinical practice and therapeutic trials.

xxiv The Timed Up and Go test (TUG) is a simple assessment of mobility based on the time taken to rise from a standard arm chair, walk 3 meters, turn, walk back to the chair, and sit down.

xxv Disabilities of the Arm, Shoulder and Hand (DASH) accessed on–line as http://www.dash.iwh.on.ca/ measures physical function and symptoms in people with musculoskeletal disorders of the upper limb.

xxvi The Roland Morris Disability Questionnaire is a widely used health status measure for low back pain. Accessed on–line at http://www.rmdq.org/

xxvii The WOMAC and AUSCAN scales measure pain, disability and stiffness in knee and hip osteoarthritis, and hand osteoarthritis respectively. Accessed on–line at http://www.womac.org/womac/index.htm, http://www.auscan.org/auscan/index.htm

xxviii The FRAX tool evaluates fracture risk based on clinical factors and femoral neck bone density, giving a 10–year probability of fracture. Accessed on–line at http://www.shef.ac.uk/FRAX/

xxix Duel energy X–ray absorptiometry (DEXA) scanning is a form of x–ray which measured bone density.

xxx QFracture is an online tool which calculates the risk of developing any osteoporotic fracture (i.e. hip, wrist, shoulder or spine) or hip fracture. Accessed on–line at http://www.qfracture.org/

xxxi The Patient Health Questionnaire (PHQ) is a multiple–choice self–report questionnaire used as a screening and diagnostic tool for mental health disorders.

xxxii Patient Activation measures (PAM) assess a person's knowledge, skills and confidence in managing their health and healthcare.

In contrast to many areas of health, there is a lack of specific biomedical markers (equivalents of blood glucose measurement in diabetes) which can be used as objective measures of musculoskeletal health status, particularly for conditions of musculoskeletal pain such as osteoarthritis. This means that information gathered through questionnaires, including patient reported outcome measures (PROMS), can play an important role in tracking musculoskeletal health status. PROMS are available across a range of long–term conditions, and used more extensively these measures have the potential to enable better understanding of health outcomes achieved in care planning at an individual and system level.

M–PROM

Arthritis Research UK is supporting the development and clinical evaluation of a patient reported outcome measure for musculoskeletal conditions (the M–PROM).[xv]

The M–PROM questionnaire is intended for use by people with a range of musculoskeletal conditions. It will enable people to self–assess their musculoskeletal health, supporting self management and shared decision making. The M–PROM will also provide a means of sharing information with health professionals throughout the healthcare services that people with musculoskeletal conditions use, including in primary and secondary care, physiotherapy, orthopaedics and rheumatology.

Figure 10 illustrates source of information which may be gathered by healthcare professionals to assess the impact of the musculoskeletal conditions on health and wellbeing. Not all measures will be appropriate for an individual. Assessment of pain should be a component of care planning for people with musculoskeletal conditions.

How might people with musculoskeletal conditions use care planning?

Supporting musculoskeletal and mental health, and the role of allied health professionals:

Jeremy is 45 and has lower back pain which comes and goes, but has gradually worsened over the last 5 years. In bad periods the pain prevents him sleeping and he has to take sick leave from his job as a delivery man lifting heavy boxes. His mood is affected when he can't work because he feels pressure to provide for his family, and a year ago he was prescribed antidepressants. Jeremy's physiotherapist helped him to write a day–to–day monthly exercise plan, and they agreed to meet every 6–12 weeks to review his progress.

5.6 Review frequency

Group	1. Inflammatory conditions	2. Conditions of musculoskeletal pain	3. Osteoporosis and fragility fractures
Review frequency	Annual	Every 1–3 years	Every 1–3 years

Care planning reviews should take place at a frequency agreed by the individual involved. Review frequency will vary depending on the type of musculoskeletal condition, although in broad terms the offer of a review each year can be a hopeful reminder, prompting people to consider their health and whether they need further support.

For people with inflammatory forms of arthritis an annual review would align with NICE clinical guidance and be appropriate for people with stable or low disease activity.[46] More frequent review may be needed in the first months after diagnosis and following a flare. For people with conditions of musculoskeletal pain a review frequency of between one and three years may be sufficient. NICE clinical guidance for osteoarthritis recommends an annual review for people 'with troublesome joint pain, more than one joint with symptoms, more than one comorbidity, or for people taking regular medication for their osteoarthritis.' For people with osteoporosis or at risk of fragility fracture, a review frequency of 1–3 or 1–5 years may be sufficient, depending on their level of risk.

5.7 Commissioning services

An important outcome of a care planning consultation is the agreement of actions that the person can follow to improve or maintain their health and wellbeing. This is supported by the local availability of services and facilities which people can incorporate into their plan. These should not only include health and social care services, but a broader range of facilities which may be provided by local councils, the voluntary or commercial sector and which people value in maximising their quality of life. Healthcare professionals involved in care planning should be able to advise people about the services available in their area.

People with musculoskeletal conditions benefit from access to allied health professional services (e.g. physiotherapy) and it is important and these services are considered as part of action planning, and are locally available. Wider services that can particularly benefit people with musculoskeletal health conditions include exercise facilities and social clubs. In broad terms, there is a need for services which are 'able–ing', in that they are built around people's strengths and support people to be independent, rather than compensating for ill–health and building dependency.[47] Services should be developed with people rather than diseases and conditions in mind.[48]

Besides the services themselves, there is a need for musculoskeletal awareness and knowledge in healthcare professionals and in people working in community settings. Appropriate training should be undertaken. For example, gym staff should understand the benefits of physical activity for people with musculoskeletal conditions and be able to provide advice on appropriate forms of exercise.

How might people with musculoskeletal conditions use care planning?

Using technology and supporting changes in life-style:

Steve is 16 and passionate about going to University to study Italian. He's had juvenile idiopathic arthritis since he was 7 and knows his local rheumatology team well. His condition is stable but he has fluid removed from his knees when they flare. With his rheumatology nurse's help, Steve found a way of storing most of his results and records on-line and has converted his care plan into mobile phone alerts. Once he's left home he'll be reminded to think about his health every two weeks, and to get an appointment with his new rheumatology team once a term.

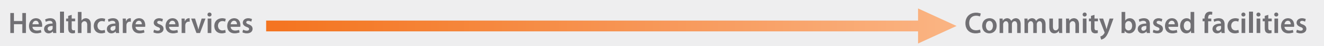
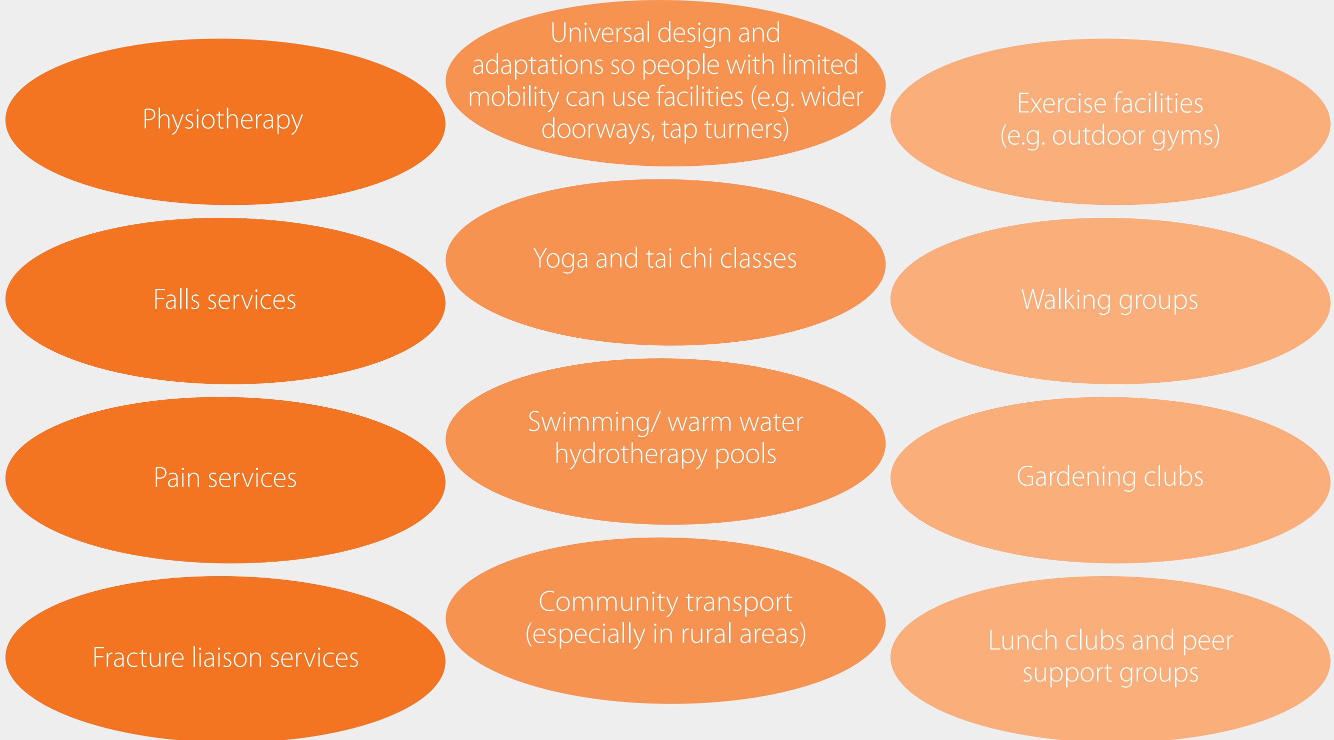


Figure 11: Examples of services which enable people with musculoskeletal conditions to maintain and improve their health



6. CARE PLANNING AND MULTIMORBIDITY

6.1 Co and multimorbidity

Although the number of people with a long term condition is predicted to remain relatively constant at around 15 million in England over the next decade, the number of people living with *more than one* long term condition is increasing.[49] The proportion of general practice consultations for people with multimorbidities is already high (78%) and the challenges of addressing multimorbidity will place further demand on healthcare services.[50] Multimorbidity is more common in the elderly, although the overall number of people living with multimorbidities is greater in those under 65. It is strongly associated with socioeconomic status, and in the most deprived areas multimorbidity can develop 10–15 years before it does in more affluent areas.[51] Current healthcare systems are rarely well configured to address the challenges of multimorbidity. However, care planning can offer part of the solution.

Figure 12: Comorbidity and multimorbidity

Comorbidity: A comorbid condition is one which a person has together with and because of another condition. For example, many people with rheumatoid arthritis (or diabetes) develop cardiovascular disease as a comorbidity.

Multimorbidity: Many people develop more than one long–term condition simultaneously, without the conditions being causally linked. These conditions can be referred to as 'multimorbidities'. For example, somebody with osteoarthritis may also have hearing loss, or a person with osteoporosis may also have mental illness.

In reality the links between conditions cannot always be clearly defined, and inter–relationships between different symptoms in a multimorbid person are complex.

6.2 Musculoskeletal conditions as part of multimorbidity

The high prevalence of musculoskeletal conditions means that they are a major contributor to multimorbidity. One in five of the registered population consults a GP each year about a musculoskeletal condition, and over 8.75 million people living in the UK have sought treatment for osteoarthritis in general practice.[52] Estimates suggest that 82% of people with osteoarthritis, the most common form of arthritis, have at least one other long term condition such as hypertension, cardiovascular disease or depression.[53]

Pain is common in people with multimorbidities, and cuts across a range of long term conditions. Painful conditions, including musculoskeletal conditions such as osteoarthritis, are among the most common comorbidities found in people with depression, coronary heart disease, chronic obstructive pulmonary disease and diabetes. Conversely, people with painful conditions often have other long term conditions, particularly hypertension or depression.[54] Depression is found more commonly in people with persistent pain than those without.[55]

Musculoskeletal health is an important contributor to overall health and wellbeing, and can increase severity of other conditions or limit treatment approaches. For example, osteoarthritis of the knee can act as a barrier to exercise which is an essential part of the treatment of people with diabetes, respiratory or cardiovascular disease.

Given the close interrelationships between musculoskeletal health and overall health it is essential that musculoskeletal health is routinely considered during care planning for people with any long term condition, including those with multimorbidities. All care planning conversations should consider musculoskeletal symptoms, including persistent pain and its impact on function, mobility and wider health and wellbeing.

6.3 Challenges for care planning in multimorbidity

Addressing people's health and wellbeing needs is more challenging as the number of conditions they have increases.[56] For people with multimorbidities increasing coordination of care can improve outcomes. People with multimorbidities value convenient access to health care, individualised care plans, support from one coordinator of care, and continuity of relationships with healthcare professionals. They also value healthcare providers with a caring attitude and listening skills, who can appreciate that their needs are unique and often fluctuating.[57,58]

'The practical issues, and clinical challenges of care planning with people with multiple and complex LTCs remain great, but those testing delivery of the care planning process believe they will not be insoluble.' [59]

Healthcare services have traditionally been organised along disease–specific lines. Treating diseases in isolation can reduce coordination of care. The need for multiple clinic attendances can be inconvenient or confusing, and particularly difficult for people with musculoskeletal conditions and limited mobility – in comparison to the burden or impact of disease on a person's life this is sometimes referred to as the 'burden of care'.[60] By taking a holistic approach, and providing the opportunity for a person–centred discussion, care planning has the potential to overcome these factors and to improve the quality of care for people with multimorbidities. The challenge, which care planning can help to address, is to configure services around the needs of the person and to meet them as effectively and efficiently as possible.

A further challenge is in ensuring that healthcare professionals who work with people with multimorbidity are skilled in integrating issues so that they can develop care planning goals that are holistic and relate to individual preferences. Healthcare professionals need training to manage the complexity of multimorbidity and musculoskeletal core skills should be included within this.[61]

Figure 13: Core skills in musculoskeletal care

Arthritis Research UK has funded and jointly developed the *Core skills in musculoskeletal care programme* with the Royal College of General Practitioners. The programme addresses the challenge that many GP Specialist Trainees do not currently receive formal training in musculoskeletal problems. The course emphasises a consistent clinical approach – effective history–taking, simple examination, making and explaining diagnosis and forming an appropriate management plan – using clinical examples to demonstrate different aspects of care.[62]

Arthritis Research UK has identified practice nurses as being a key group of healthcare professionals who work with many people with long term joint pain in the context of consultations about long term conditions. The charity is working with Education for Health to provide an online training course and practical workshops for practice nurses and Allied Health Professionals. *Assessing and managing patients with joint pain* is a six–month degree–level module, accredited by the Open University, which aims to give nurses and associate practitioners knowledge, skills and confidence to offer help and support to people with musculoskeletal conditions – particularly in the context of multimorbidity and long term conditions management.[63]

Some general practices and other healthcare settings currently lack the organisational structure necessary to support the care planning process for multimorbidity. Healthcare professionals are frequently based in different locations, and it can be challenging to coordinate input into care planning from a range of specialists. This is particularly true for musculoskeletal conditions where a high number of different and allied health professionals can be involved. A mechanism which would facilitate care planning is the development of a single unified set of (electronic) notes accessible to the person, their nominated carers/advocate and the health and social care professionals involved.

'Only two practices co–ordinated appointments so that patients with multimorbidities would be seen in one appointment. Multimorbidity in this context however was defined as diabetes, respiratory and cardiac conditions or chronic kidney disease. A patient with arthritis and chronic obstructive pulmonary disease for example would still need to attend two separate appointments. Three practices did try to combine the review for diabetes and CHD as the clinical monitoring and advice were similar. Some healthcare professionals also dealt with multimorbidity opportunistically, but there was no formal structure to ensure this happened.' [64]

Figure 14: Care planning, information technology and access to records

One of the challenges to implementing care planning, identified by the Year of Care programme, was the lack of appropriate templates and IT systems to enable the components of care planning to be captured as part of the routine clinical record.[65] Although some local solutions have been developed this remains an on–going challenge and systems need to be available to ensure that plans can be effectively produced, shared and stored within agreed bounds of confidentially.

By April 2015, all GP practices should have systems in place to enable patients to access some information contained in their own Summary Care Record (SCR) and GP practices may begin to offer access to information beyond this minimum.[66] It is important to consider how greater access to their records could support self–management by people with long term conditions. Current examples of patient–held records include the Personal Child Health Record (PCHR or 'Red Book') which is updated by Healthcare Professionals but held and retained by parents on behalf of their child.[67]

A further challenge is in ensuring that the benefits of standardised processes and financial incentives can be achieved *alongside* care that considers the individual priorities and needs of people with multimorbidity. In general practice, there can be tension between the need for compliance with disease specific guidelines, and a culture which fosters and enables opportunities for holistic aspects of care for people with multimorbidity to be discussed.

'The reality for increasing numbers of people is that they will be living with more than one long–term condition. The future for care planning therefore needs to be about whole–person care not single–disease care and the system levers including service configuration and financial incentives needs to align to support this approach.' [68]

Nurses involved in care planning people with diabetes, gave their perspectives on the benefit and limitations of care planning for people with multimorbidity:

'Care planning is useful, it's not for everyone… is holistic up to a point and does allow exploration of issues but is directed in some ways by the disease rather than the whole person, who in reality will have more than one long–term condition'

'We are diagnosing people a lot younger (with type 2 diabetes) so they have fewer comorbid conditions, so their engagement in the care planning process varies. But it can be really heartening to have patients you would not necessarily expect coming in with a folder with their results in'

'The process could be made broader to cover other long–term conditions'. [69]

A small number of pilots have systematically investigated self–management in people with multimorbidity to date.

Figure 15: Examples of self–management pilots in people with multimorbidity

Year of Care: NHS North East and Tower Hamlets. A care planning pilot in NHS North East based on the Year of Care approach included people with more than one long term condition. Nine out of ten practices found advantages in using care planning in this way. Practices within the NHS Tower Hamlets pilot are extending approach to people with a wider range of conditions, including people with cardiovascular disease.[70]

The Inner North West London integrated care pilot was a large scale programme focused on developing new forms of care coordination and planning for people with diabetes and those over 75 years of age. An initial evaluation concluded that 'better care planning has real potential to improve patients' experience of care, in particular in reducing duplication and improving access to services'.[71]

The Chronic Illness Care Management model introduced in Ontario, Canada used a holistic, patient centered, and pragmatic approach to improve the management of chronic disease in Canadian family practice, and focused on patients aged 50 or over with multiple long–term conditions. This work found that organisational and financial constraints, as well as family physicians' concepts of their role and their view of patients' abilities to partner in care management acted as barriers to implementation.[72]

As care planning is more widely implemented, research should be undertaken in patients with multimorbidities to further define effective care planning processes. Health services research should consider how the care planning could be embedded for people with multimorbidity in different healthcare settings, and its economic impacts. Increased coordination of research effort between organisations to identify the commonalities of care planning across disease areas would also be beneficial.

6.4 Care and support planning

Although initial care planning programmes have been based in healthcare among people with long term conditions, the approach has much wider value. Care and support planning is already in use within social care settings, including by people living in care homes and by people with complex needs such as drug or alcohol dependency. Its use is being further extended into groups including cancer survivors, the frail and elderly, people at the end of life (including anticipatory care planning), those with learning disabilities, and women during pregnancy. Many people within these groups will have musculoskeletal conditions.

In 2012, National Voices developed a narrative to foster shared understanding of care and support planning amongst people working across health and social care sectors. This is given from the perspective of the individual involved: *'My care is planned with people who work together to understand me and my carer(s), put me in control, co–ordinate and deliver services to achieve my best outcomes.*'[73] The recent 'guide to care and support planning' considers how different aspects of life including housing, work and employment, sensory loss can be considered within care and support planning.[74] As care and support planning becomes more widely implemented, greater awareness of the nature and impact of musculoskeletal conditions may be needed by people working across social care sector and in community care settings to ensure that people's musculoskeletal health needs can be taken into account.

Figure 16: The Coalition for Collaborative Care

Arthritis Research UK is a member of the Coalition for Collaborative Care. Launched in March 2014, this is a group of individuals and organisations across the health, social care and voluntary sectors who are working to make person–centred, coordinated care a reality for people living with long–term conditions. The coalition will work to improve the relationship that people have in their day–to–day interaction with the NHS and social care so their care and support is organised around what matters to them.[75]

7. LOOKING AHEAD

7.1 Recommendations

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'.[76] 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'.

8. ANNEXES

8.1 Workshop programme, participants and extracts

The 'Care planning for people with musculoskeletal conditions' workshop was held on Thursday 20 June 2013 at the Royal Institute of British Architects (RIBA), 66 Portland Place, London.

Background:

NHS England's Mandate includes a commitment to ensure that 'everyone with a long–term condition… will be offered a personalised care plan…' Building on the development of care planning and the 'Year of Care' programme in diabetes, there is current momentum to extend the care planning approach across long–term conditions, and to accelerate its implementation in the NHS. At this time, it is important to ensure that all health professionals involved in care planning should be alert to the presence of musculoskeletal conditions as a major comorbidity, and that the benefits of care planning can be fully realised by people with conditions such as osteoarthritis and inflammatory arthritis.
This workshop will consider and help to define the care planning process in relation to musculoskeletal conditions.

Programme:

Introduction

Welcome
Chair: Alan Silman, Medical Director, Arthritis Research UK

Introduction
Alan Silman, Medical Director, Arthritis Research UK
Laura Boothman, Policy Manager, Arthritis Research UK

Care planning and the Year of Care Programme
Sue Roberts, Chair, Year of Care Partnerships

An individual perspective on care planning
Rob Hemmings

Discussion sessions

1 The care planning consultation for people with musculoskeletal conditions
Facilitated by: Jo Protheroe, Senior Lecturer in General Practice, NHS Manchester
Activity: A care planning 'results and prompt sheet' for musculoskeletal conditions
Feedback and wider discussion

2 Musculoskeletal conditions, multi–morbidity and services
Facilitated by: Tom Margham, Lead for Primary Care, Arthritis Research UK
Activity: Accessing services following a care planning consultation
Feedback and wider discussion

Implementing care planning – wider perspectives

Chair: Alan Silman, Medical Director, Arthritis Research UK

Care planning and long–term conditions – an NHS England/DH perspective
Alison Austin, Personalisation and control lead, NHS England
A common narrative and 'ten principles' for care planning
Laura Robinson, Policy and Communications Advisor, National Voices

Care planning across long–term conditions
Nigel Mathers, Vice Chair, Royal College of General Practitioners

Discussion

Close

Workshop participants:

Alan Silman [Chair]	Medical Director, Arthritis Research UK
Nona Ahamat	Head of Policy, The British Society for Rheumatology
Alison Austin	Personalisation and Control Lead, NHS England
Phil Baker	Acting CEO, Arthritis Care
Laura Boothman	Policy Manager, Arthritis Research UK
Amanda Cheesley	Long Term Conditions Adviser, Royal College of Nursing
Ann Clare	Arthritis and Musculoskeletal Alliance (ARMA)
Benjamin Ellis	Senior Clinical Policy Advisor, Arthritis Research UK
Amy Forbes	Policy Officer, Arthritis Research UK
Iain Gilchrist	Primary Care Rheumatology Society
Rob Hemmings	NHS Bristol
Nick Lewis–Barned	Clinical Fellow, Shared Decision Making and Support for Self Management, Royal College of Physicians (RCP)
Tracey Loftis	Head of Policy & Public Affairs, Arthritis Research UK
Tom Margham	Lead for Primary Care, Arthritis Research UK
Nigel Mathers	Vice Chair, Royal College of General Practitioners Council
Beverley Matthews	Programme Director & Transition Lead – Domain 2 Delivery Team at NHS Improving Quality
Marianne Morris	Principal Lecturer in Health Psychology, University of West England
Jo Protheroe	Senior Lecturer in General Practice, Keele University & NHS Manchester
Maddy Randell	Branch Development Officer, National Ankylosing Spondylitis Society
Sue Roberts	Chair, Year of Care Partnerships, Northumbria Healthcare NHS Foundation Trust
Laura Robinson	Policy and Communications Advisor, National Voices
Neil Snowden	Consultant Rheumatologist, Pennine MSK Partnership
Ruth ten Hove	Professional Adviser, Health Informatics team, Chartered Society of Physiotherapists (CSP)

Extracts from presentations:

The following short extracts are intended to reflect the perspectives of the speakers at the workshop. Further information is available on–line at http://www.arthritisresearchuk.org/policy–and–public–affairs/policy–priorities–and–projects/musculosketal–health–services/care–planning.aspx.

'Seventeen years ago, I experienced a sudden onset of arthritis, which began in the night. I was in excruciating pain and was admitted to hospital, unable to move. Although I began to recover, I later developed fibromyalgia and had to stop work… After years of being a passive patient, I went on a pain management programme… Care planning can give a framework to build on, although it's not 'one size fits all' … Having prepared for the consultation, you can lead the conversation, not the doctor.'

Rob Hemmings

'Care planning is about ensuring better conversations for everyone – it's a process of both involvement and support … identifying what matters to each person … helping them move on, become better problem solvers and live a good life.'

Sue Roberts, Chair, Year of Care Partnerships

'More than 15 million people in the England are living with long–term conditions, and the numbers of people with co–morbidity is predicted to rise within the next decade… Acute focused, episodic single disease models will not work in future. We need to adopt a holistic, personal approach to providing care. We will need proactive, personalised care planning to support and manage multiple morbidities. We will need patients to be active partners, in control of their own care, self–managing – and supporting each other.'

Alison Austin, Personalisation and Control Lead, NHS England

'Care and support planning makes sure we see people as people, not conditions or disabilities. Those who have tried it – both people who use services and professionals – see it as a better way to work together. Get it right and we will have real, person–centred care. Many people who could benefit haven't yet heard of care and support planning. Our work in this area seeks to change this.'

Laura Robinson, Policy and Communications Advisor, National Voices

'The aims of the RCGP's care planning programme are to embed care planning into the 'core business' of General Practice; to incorporate the development of care planning skills into the GP training curriculum and to facilitate other educational initiatives for established GPs… The vision is for care planning to be the norm.'

Nigel Mathers, Vice Chair, Royal College of General Practitioners Council

'The reality for increasing numbers of people is that they will be living with more than one long–term condition. The future for care planning therefore needs to be about whole–person care not single–disease care. I think that care planning works best when it is approached less like a process and more as an ethos of care – working collaboratively with patients, sharing information and identifying goals to get the best outcomes.'

Tom Margham, GP and Lead for Primary Care, Arthritis Research UK

'Future care planning programmes must take health literacy into account. People can only decide on actions to support their health if they really understand the discussion and the options open to them. Care planning must be about a person bringing their aims and priorities to the discussion in terms that mean something to them, and the health professional sharing information in a way that is accessible. If this works well, a shared understanding can be reached and informed plans, that are more likely to work in practice, can be made.'

Jo Protheroe, Senior Lecturer in General Practice, Keele University & NHS Manchester

'We are considering how care planning can be used effectively by people living with musculoskeletal conditions as a way of self–managing their health. How do people with musculoskeletal conditions fit into the wider context of people living with long–term conditions who may use care planning – and what particular needs might they have? People with musculoskeletal conditions often use care from multiple providers, and so coordination of care across different settings is an important factor to take into account.'

Alan Silman, Medical Director & Director of Policy and Health Promotion, Arthritis Research UK

8.2 Care planning in legislation and policy

Legislation	Content related to care planning	Remit
Care Act (2014)	Legislation requires local authorities to involve people in the development of their care and support plan, and to review the plan at the request of the adult involved or their carer.[77]	Social care
The Health and Social Care Act (2008) (Regulated Activities) Regulations (2010)	Promotes service user participation in decision, by encouraging them to 'understand the care or treatment choices available' and 'express their views as to what is important to them in relation to the care or treatment'.[78]	Health care
National Health Service and Community Care Act (1990)	Care plans to be developed by local authorities for people needing community care services.[79]	Social care
Policy		
The Mandate. A mandate from the Government to NHS England April 2014 to May 2015	Objective: 'everyone with long–term conditions, including people with mental health problems, will be offered a personalised care plan that reflects their preferences and agreed decisions'.[80]	Health care
Consultation on strengthening the NHS Constitution: Government response	New pledge to: 'involve you in discussions about planning your care and to offer you a written record of what is agreed if you want one.'[81]	Health care
The NHS Outcomes Framework 2014/15	Indicator 2.1 'proportion of people feeling supported to self–manage their condition'.[82]	Health care
The Mandate. A mandate from the Government to the NHS Commissioning Board: April 2013 to March 2015	Objectives: 'To ensure the NHS becomes dramatically better at involving patients … empowering them to manage and make decisions about their own care and treatment.' 'By 2015 … more people will have developed the knowledge, skills and confidence to manage their own health…everyone with LTCs including mental health problems, will be offered a personalised care plan that reflects their preferences and agreed decisions.'[83]	Health care
Liberating the NHS: No decision about me, without me – Government response to the consultation	Recognition of importance of care planning; commitment to look at ways to strengthen the role of care planning.[84]	Health and social care
High Quality Care for all. NHS Next Stage Review Final Report ('Darzi Report')	By 2010 'every one of the 15 million people with one or more long–term conditions should be offered a personalised care plan, developed, agreed and regularly reviewed with a named lead professional from among the team of staff who help manage their care'.[85]	Health and social care

Policy		
Our health, our care, our say: a new direction for community services	'By 2008 we would expect everyone with both long–term health and social care needs to have an integrated care plan if they want one. By 2010 we would expect everyone with a long–term condition to be offered a care plan'.[86]	Health and social care
Care Programme Approach	Formation of a care plan which identifies the health and social care needs of people accepted into specialist mental health services.[87]	Health services (mental health)

8.3 Care planning in NICE Guidance for musculoskeletal conditions

NICE Clinical Guidance	Content which relates to the self–management and/or a care planning approach
CG79 Rheumatoid arthritis.[88]	• Opportunities to talk about and agree all aspects of care • Offer of verbal and written information to improve understanding of the condition and its management • Opportunity to take part in self–management programmes • Review appointments at a frequency and location suitable to needs • An annual review
CG153 Psoriasis.[89]	• Discussion of the risks and benefits of treatment options with the person (and their families and carers where appropriate) • Treatment strategy developed to meet the person's health goals • Assessment of disease severity should include the patient's own assessment • Offer of support and information tailored to suit individual needs and circumstances • Annual assessment for psoriatic arthritis
CG177 Osteoarthritis.[90]	• A plan agreed with the person (their family members or carers) for managing their osteoarthritis, following the principles of shared–decision making • Discussion of the risks and benefits of treatment options, taking into account comorbidities • An offer of appropriate information to enhance understanding of the conditions and its management; information sharing that is ongoing and an integral part of the management plan rather than a single event • Agreed individualised self–management strategies • Self–management programmes (individual or group) • Offer of a regular review, including: monitoring the impact and course of the condition, discussion of concerns and preferences, review of treatment tolerability, support for self–management. The timing of the review should be agreed • An individualised approach which meets patient experience principles and has regard to their views and preferences
CG88 Low back pain.[91]	• Provision of advice and information to support self–management • Person's expectations and preferences taken into account when treatments are considered

NICE Clinical Guidance	Content which relates to the self–management and/or a care planning approach
CG124 Hip fracture.[92]	• Identification of individual goals for multidisciplinary rehabilitation to recover mobility and independence • Continued, coordinated orthogeriatric and multidisciplinary review • Offer (to patient, or carer/family) of verbal and printed information about treatment and care
CG146 Osteoporosis fragility fracture.[93]	• N/A
CG161 Falls.[94]	• Older people should be routinely asked whether they have fallen in the past year • Discussion of the changes a person is willing to make to prevent falls • Falls prevention packages should address potential barriers such as low self–efficacy • Falls prevention packages should accommodate participants' different needs and preferences • Offer to individuals, and carers, of information orally and in writing
QS33 Rheumatoid arthritis.[95]	• People with rheumatoid arthritis are offered educational activities and self–management programmes within 1 month of diagnosis • People with rheumatoid arthritis have a comprehensive annual review that is coordinated by the rheumatology service
QS40 Psoriasis.[96]	• People with psoriasis are offered an assessment of how their physical, psychological and social wellbeing is affected by having psoriasis when they are diagnosed and when their response to the treatment is assessed • Adults with severe psoriasis are offered an assessment of their risk of having heart problems when they are diagnosed and at least once every 5 years • People with psoriasis having treatment are offered an annual assessment for psoriatic arthritis
NICE QS16 Hip fracture.[97]	• People with hip fracture are offered an assessment to identify their risk of falling in the future, and are offered help tailored to their circumstances to reduce these risks if needed

8.4 Care planning in ARMA standards of care for musculoskeletal conditions[98]

ARMA Standard of Care	Content on care planning:
Back pain	• N/A
Connective tissue disease	• Standard 8 (Individualised care plans): A plan for ongoing care should be offered and agreed between the patient and the multidisciplinary team. This should give constructive messages about the patient's condition and the roles for the patient and the multidisciplinary team and other relevant parties, e.g. family or employers, in the management of their condition. This care plan should draw on good clinical practice, and consider any alternative or complementary therapies that the patient may be taking. It should be based on current guidelines and evidence where available.
Musculoskeletal foot health	• Standard 10 (Individualised care plans): On diagnosis or on the basis of a management plan, an appropriate, individualised plan for ongoing care should be jointly developed by the foot health provider, the service user, carer and relevant members of the multi–disciplinary team. A printed copy of the care plan should be provided for the service user.
Gout	• N/A
Inflammatory arthritis	• Standard 7 (Individualised care plans): People should be offered an individualised care plan for ongoing care.
Juvenile idiopathic arthritis	• Subsection of Standard 7 (Evidence–based care): Children and young people with JIA should have safe, effective, evidence–based care and management strategies with appropriate monitoring arrangements as defined by recognised professional bodies... An individualised care plan can enable a child or young person and their family to have a clear understanding of what they can expect. It identifies who is responsible for which aspects of care, and promotes collaboration between the person and all the professionals involved.
Metabolic bone disease	• N/A
Osteoarthritis	• Standard 5 (Individualised care plans): On diagnosis people should be offered a care plan giving constructive messages about their condition. Developmental: People with joint pain and/or a diagnosis of osteoarthritis should have access to a health worker, who can work with them in developing an individualised care plan and in making informed choices about treatments, providers and services.
Regional musculoskeletal pain	• Standard 8 (Individualised care plans): On diagnosis, people should be offered an appropriate individualised plan for ongoing care. This should give constructive messages about their condition and the roles for the patient and the multidisciplinary team and other relevant parties, e.g. employers, in the management of their condition. This care plan should draw on good clinical practice and be evidence–based. The health practitioner should work with the service user to identify possible triggers or causes of their condition and to build joint solutions for the monitoring and management of their condition.

8.5 Methodology for data analysis

Data on the use of care plans in this report are taken from two national surveys:

1. The Health Survey for England
2. The General Practice Patient Survey

The Health Survey for England provides a representative sample of the population at both national and regional level.[99] Participants (children and adults) are selected using a random postcode search across England and surveyed by interview. Data are also collected through nurse visits.

Analysis of 2009, 2010 and 2011 survey data has been made using the on–line analysis tool (including cross–tabulation) accessible through the UK Data Archive: http://www.data–archive.ac.uk/. Definitions used within the survey are:

» People with long term conditions are identified by a positive response to the question: Do you have any have any physical or mental health conditions or illnesses lasting or expected to last 12 months or more?

Other health conditions are coded as:

» Musculoskeletal system conditions: One or more of arthritis/rheumatism/fibrositis; back problems/slipped disc/spine/neck; other problems of bones/joints/muscles.

» Mental health conditions: One or more of mental illness/anxiety/depression/nerves; mental handicap.

» Respiratory: One or more of bronchitis/emphysema; asthma; hayfever; other respiratory complaints.

» Heart and circulatory: One or more of stroke/cerebral haemorrhage/cerebral thrombosis; heart attack/angina; hypertension/high blood pressure/blood pressure; other heart problems; piles/haemorrhoids including varicose veins in anus; varicose veins/phlebitis in lower extremities; other blood vessels/embolic.

Health Survey for England data on care plans and long term conditions

Survey year	2009	2010	2011
Number of people (adults, children)	8602 (4645, 3957)	14112 (8420, 5692)	10617 (8610, 2007)
Number of people with a long term condition	2088	3793	3709
Number of people with a long term condition and a care plan	332	540	413
% of people with a long term condition who have a care plan	15.9	14.2	11.1
Number of people with a musculoskeletal condition	828	1553	1594
Number of people with a musculoskeletal condition and a care plan	100	194	180
% of people with a musculoskeletal condition who have a care plan	12.1	12.5	11.3

Health Survey for England data on the care plans and long term conditions					
Condition	**Mental health**	**Metabolic disease**	**Respiratory**	**Heart and circulatory**	**Musculoskeletal**
Number of people with condition	344	795	720	1077	1594
Number of people with condition with a care plan	97	135	96	133	180
% of people with the condition and a care plan	28.2	16.9	13.3	12.3	11.3

All data taken from the 2011 Survey

The General Practice Patient Survey (GPPS) assesses patients' experiences of access to and quality of care received from local GPs, dentists and out–of–hours doctor services.[100] Patients' experiences of NHS primary care services are recorded as well as their general state of health. The survey is sent twice a year (January and July) across two waves of fieldwork to approximately 2.7 million randomly selected adult patients registered with a GP in England and participation is voluntary. For the two waves of results published in December 2013, 35% of those selected returned a completed questionnaire. In July 2013, as part of the second wave of fieldwork, a new subset of questions were included in the survey asking patients about written care plans.

Analysis of the results from the survey is routinely carried out by NHS England's Central Analytical Services Team (Patients and Information).

Definitions used within the survey are:

- People with long term conditions are identified by a positive response to the question: Question 30: 'Do you have a long standing health condition?' Question 31 lists 15 specific conditions plus an 'other' category.
- People with a written care plan are identified by a positive response to the question: Question 36: 'Do you have a written care plan?'

General Practice Patient Survey data on the care plans and long term conditions	
Number of respondents	431,272
Number of respondents with a written care plan	13,524
% of respondents with a written care plan	3.1
Number of respondents with arthritis or a long term joint problem	50,618 (wave 2)
Number of people with arthritis or a long term joint problem with a written care plan	2,794
% of people with arthritis or a long term joint problem with a written care plan	5.5
Number of respondents with a long term back problem	39,644
Number of people with a long term back problem with a written care plan	1,847
% of people with a long term back problem with a written care plan	4.7

Data taken from second wave of General Practice Patient Survey 2013

8.6 References

1. Department of Health (November 2013). The Mandate. A mandate from the Government to NHS England April 2014 to May 2015.
2. Royal College of General Practitioners Birmingham Research Unit (2006). Annual prevalence report.
3. The Health Foundation (April 2012). Co–creating health: Evaluation of the first phase.
4. The Kings Fund (2013). Delivering better services for people with long–term conditions. Building the house of care.
5. National Voices (2014). Care and support planning guide. Accessed at http://www.nationalvoices.org.uk/read–our–guide
6. Department of Health (1990). Care programme approach. Health Service Circular/ Local Authority Circular HC(90)23/LASSL(90)11.
7. Year of Care (June 2011). Report of findings from the pilot programme.
8. Coalition for collaborative care (2014). Accessed at http:// coalitionforcollaborativecare.org.uk/house–of–care/
9. Department of Health and Diabetes UK (2006). Care Planning in Diabetes. Report from the joint Department of Health and Diabetes UK Care Planning Working Group.
10. Royal College of General Practitioners Clinical Innovation and Research Centre (2011). Care Planning Improving the Lives of People with Long Term Conditions.
11. National Voices (2014). Care and support planning guide. Accessed at http://www.nationalvoices.org.uk/read–our–guide. A care planning guide/toolkit for healthcare professionals is in production.
12. Department of Health (November 2013). The Mandate. A mandate from the Government to NHS England April 2014 to May 2015.
13. British Medical Association, NHS England, NHS Employers (March 2014). General medical services contract 2014/15. Guidance and audit requirements.
14. Care Act (2014). Accessed at http://services.parliament.uk/bills/2013–14/care.html
15. Arthritis Research UK (2010). Working in partnership towards a future free from arthritis: our research strategy 2010–2015.
16. Department of Health (February 2014). 2012–13 Programme budgeting benchmarking tool. Accessed at http://www.networks.nhs.uk/nhs–networks/health–investment–network/news/2012–13–programme–budgeting–data–is–now–available
17. Arthritis Research UK National Primary Care Centre, Keele University (2009). Musculoskeletal Matters.
18. Arthritis Research UK (July 2013). Understanding Arthritis. A parliamentary guide to musculoskeletal health.
19. Fibromyalgia association UK (October 2013). Personal care plan for people with fibromyalgia.
20. Symmons D et al (2002). The prevalence of rheumatoid arthritis in the United Kingdom: new estimates for a new century. Rheumatology 41(7):793–800.
21. Arthritis Research UK (2013). Osteoarthritis in general practice.
22. National Osteoporosis Society (2011). A fragile future: 25th anniversary report.
23. Arthritis Care (2012). OA Nation 2012.
24. Department of Health (November 2013). The Mandate. A mandate from the Government to NHS England April 2014 to May 2015.
25. National Institute for Health and Care Excellence (February 2014). Osteoarthritis. Care and management in adults. NICE Clinical guideline 177.
26. Arthritis and Musculoskeletal Alliance (ARMA) Standards of Care Documents. Accessed at http://arma.uk.net/resources/#Standardsofcare
27. Arthritis Care (2012).Three wasted years: evaluation progress in delivering improvement in rheumatoid arthritis services.
28. National Rheumatoid Arthritis Society (2010). The Year of RA One Year On.
29. Arthritis Care (2012). OA Nation 2012.
30. The Health Foundation (2012). Calderdale and Huddersfield NHS Foundation Trust. Accessed at http://www.health.org.uk/areas–of–work/programmes/co–creating–health/related–projects/calderdale–and–huddersfield–nhs–foundation–trust/
31. Wallace L et al., The Health Foundation (April 2012). Co–creating Health: Evaluation of the first phase: An independent evaluation of the Health Foundation's Co–creating Health improvement programme.
32. Advancing Quality Alliance, Rightcare shared decision making programme (2013). Your Health – Your Decision Evaluation & Output Report of the AQuA Workstream within the National Shared Decision Making Programme.
33. Year of Care (June 2011). Report of findings from the pilot programme.
34. The Health Foundation (March 2014). Helping measure person–centred care.
35. Year of Care (June 2011). Report of findings from the pilot programme.
36. Taken from interview with nurses from Jubilee Street Practice, Tower Hamlets.
37. Arthritis Care (2012). OANation 2012
38. Advancing Quality Alliance (2014) accessed at http://www.advancingqualityalliance.nhs.uk/sdm/
39. Taken from interview with nurses from Jubilee Street Practice, Tower Hamlets.
40. Taken from a workshop participant.
41. NHS England (2013). Frequently Asked Questions. Independent prescribing by physiotherapists and podiatrists. Accessed at http://www.england.nhs.uk/wp–content/uploads/2013/08/faqs–ippp1.pdf
42. Taken from workshop participant (GP).
43. Podsiadlo D et al. (1991). The Timed Up & Go: A test of basic functional mobility for frail elderly persons. J Am Geriatr Soc; 39:142–8.
44. Greene J et al. (2012). Why does patient activation matter? An examination of the relationships between patient activation and health–related outcomes. J Gen Intern Med. 27(5), 520–6.
45. National Osteoporosis Guideline Group (March 2014). Osteoporosis Clinical guideline for prevention and treatment.
46. National Institute for Health and Care Excellence (2009).Rheumatoid arthritis. The management of rheumatoid arthritis in adults. NICE Clinical guideline 79.
47. Horne M et al., Nesta Innovation Unit (April 2013). People powered health for people, by people and with people.
48. Year of Care (May 2011). Thanks for the petunias. A guide to developing and commissioning non–traditional providers to support the self management of people with long term conditions.
49. Department of Health (November 2013). The Mandate. A mandate from the Government to NHS England April 2014 to May 2015.
50. Salisbury C et al. (2011). Epidemiology and impact of multimorbidity in primary care: a retrospective cohort study. Br J Gen Pract 1; 61: e12–21.
51. Barnett et al. (2012). Epidemiology of multimorbidity and implications for care, research, and medical education: a cross sectional study. Lancet 308 37–43.
52. Arthritis Research UK (July 2013). Osteoarthritis in general practice.
53. Breedveld F et al. (2004). Osteoarthritis: the impact of a serious disease, Rheumatology 43:1, i4–i8.
54. Barnett et al. (2012). Epidemiology of multimorbidity and implications for care, research, and medical education: a cross sectional study. Lancet 308 37–43.
55. Arthritis Research UK, British Heart Foundation, Depression Alliance, Diabetes UK, National Rheumatoid Arthritis Society, Macmillan (April 2012). Twice as likely: putting long term conditions and depression on the agenda.
56. The Richmond group (2010). How to deliver high–quality patient centred cost effective care.
57. Bayliss E et al. (2008). Processes of care desired by elderly patients with multimorbidities. Family Practice; 25: 287 293.
58. Goodwin N et al., The Kings Fund (2010). Managing people with long term conditions: An Inquiry into the Quality of General Practice in England. (Section 7).
59. Year of Care (June 2011). Report of findings from the pilot programme.
60. Salisbury C at al. (2011). Epidemiology and impact of multimorbidity in primary care: a retrospective cohort study. Br J Gen Pract 1; 61: e12–21.
61. Royal College of General Practitioners Clinical Innovation and Research Centre (2011). Care Planning Improving the Lives of People with Long Term Conditions.
62. Accessed at http://www.arthritisresearchuk.org/health–professionals–and–students/core–skills.aspx
63. Accessed at http://www.arthritisresearchuk.org/health–professionals–and–students/education–for–health.aspx
64. Bower et al. (2013). Care planning in the treatment of long term conditions – final report of the CAPITOL project.
65. Year of Care (June 2011). Report of findings from the pilot programme.
66. British Medical Association, NHS England, NHS Employers (March 2014). General medical services contract 2014/15. Guidance and audit requirements.
67. Information on the Personal Child Health Record is available from the Royal College of Paediatrics and Child Health at http://www.rcpch.ac.uk/personal–child–health–record

68. Taken from workshop participant (GP).

69. Taken from interview with nurses from Jubilee Street Practice, Tower Hamlets.

70. Year of Care (June 2011). Report of findings from the pilot programme.

71. Nuffield Trust (May 2013). Evaluation of the first year of the inner north west London integrated care pilot.

72. Russell G et al. (2008). Beyond fighting fires and chasing tails? Chronic illness care plans in Ontario, Canada. Ann Fam Med;6:146–153.

73. National Voices (2012). A narrative for person–centred, coordinated care ('integrated care'). Accessed online at http://www.england.nhs.uk/wp–content/uploads/2013/05/nv–narrative–cc.pdf

74. National Voices (2014). Care and support planning guide. Accessed at http://www.nationalvoices.org.uk/read–our–guide

75. Accessed at http://coalitionforcollaborativecare.org.uk/

76. Department of Health (November 2013). The Mandate. A mandate from the Government to NHS England April 2014 to May 2015.

77. Care Act (2014). Accessed at http://services.parliament.uk/bills/2013–14/care.html

78. The Health and Social Care Act 2008 (Regulated Activities) Regulations 2010. Accessed at http://www.legislation.gov.uk/uksi/2010/781/contents/made

79. National Health Service and Community Care Act 1990. Accessed at http://www.legislation.gov.uk/ukpga/1990/19/contents

80. Department of Health (2013).The Mandate. A mandate from the Government to NHS England April 2014 to May 2015.

81. Department of Health (2013). Consultation on strengthening the NHS Constitution: Government response.

82. Department of Health (2013). The NHS Outcomes Framework 2014/15.

83. Department of Health (2013). The Mandate. A mandate from the Government to the NHS Commissioning Board: April 2013 to March 2015.

84. Department of Health (2012). Liberating the NHS: No decision about me, without me – Government response to the consultation.

85. Department of Health (2008). High Quality Care for all. NHS Next Stage Review Final Report

86. Department of Health (2006). Our health, our care, our say: a new direction for community services.

87. Department of Health (1990). Care programme approach. Health Service Circular/ Local Authority Circular HC(90)23/LASSL(90)11.

88. National Institute for Health and Care Excellence (2009). Rheumatoid arthritis: The management of rheumatoid arthritis in adults. Clinical guideline 79.

89. National Institute for Health and Care Excellence (2012). Psoriasis: The assessment and management of psoriasis. Clinical guideline 153.

90. National Institute for Health and Care Excellence (2014). Osteoarthritis. Care and management in adults. NICE Clinical guideline 177.

91. National Institute for Health and Care Excellence (2009). Low back pain: Early management of persistent non–specific low back pain. Clinical guideline 88.

92. National Institute for Health and Care Excellence (2011). Hip fracture: The management of hip fracture in adults. Clinical guideline 124.

93. National Institute for Health and Care Excellence (2012). Osteoporosis: assessing the risk of fragility fracture. Clinical guideline 146.

94. National Institute for Health and Care Excellence (2013). Falls: assessment and prevention of falls in older people. Clinical guideline 161.

95. National Institute for Health and Care Excellence (2013). Quality standard for rheumatoid arthritis. Quality standard 33.

96. National Institute for Health and Care Excellence (2013). Quality standard for psoriasis. Quality standard 40.

97. National Institute for Health and Care Excellence (2012). Quality standard for hip fracture. Quality standard 16.

98. Accessed at http://arma.uk.net/resources/#Standardsofcare

99. Accessed at http://www.natcen.ac.uk/taking–part/studies–in–field/health–survey–for–england/about–health–survey–for–england/

100. Accessed at http://www.gp–patient.co.uk/

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