

PERSONAL HEALTH BUDGETS

perspectives from people with arthritis and
other musculoskeletal conditions





CONTENTS

| | |
|-----------------------------------------------------------------|----|
| 1. Executive summary | 4 |
| 2. Personal health budgets | 7 |
| 3. Arthritis and other musculoskeletal conditions | 9 |
| 4. Methodology | 10 |
| 5. Attitudes to personal health budgets | 11 |
| 6. Reflecting the needs of people with arthritis and its impact | 15 |
| 6.1 Care planning approach | 15 |
| 6.2 Fluctuating conditions: flexibility is needed | 16 |
| 6.3 Interventions used by people with arthritis | 17 |
| 7. Information to empower decision-making | 18 |
| 7.1 Finance | 18 |
| 7.2 Menus and case studies | 18 |
| 8. Developing supportive infrastructure | 21 |
| 8.1 Education and training for health professionals | 21 |
| 8.2 Brokers | 22 |
| 8.3 The role of charities | 22 |
| 9. Recommendations | 23 |
| Appendix I: The survey | 24 |
| i: Methodology | 24 |
| ii: Results | 24 |
| Appendix II: The one-day workshop | 25 |
| i: Methodology | 25 |
| ii: Main findings | 25 |
| Appendix III: Policy seminar | 27 |
| i: Methodology | 27 |
| ii: Extracts from presentations | 27 |
| Appendix IV: Participants | 29 |
| References | 30 |
| Acknowledgements | 31 |

1. EXECUTIVE SUMMARY

Personal health budgets aim to give people with long term conditions or disabilities greater choice, flexibility and control over the health services and support they receive. At the heart of a personal health care budget is a care plan. This helps people with a long term condition or disability to set out their healthcare and wellbeing needs, the health outcomes they want, the amount of money in the budget and how this will be spent. Care plans are developed by people with a long term condition or disability in partnership with their local NHS team, and along with input and support from voluntary or community organisations.

The Department of Health (DH) has been piloting this new way of arranging care throughout England but arthritis and other musculoskeletal conditions were not the focus of a specific pilot. Arthritis Research UK therefore undertook a number of research activities to feed into the evaluation of the pilot, and subsequent policy development by DH, to ensure the needs of people with arthritis were recognised. We undertook a survey among those living with the condition; we held a one-day workshop at DH involving health professionals, charities, policy-makers and people with arthritis, to explore the implications of personal health budgets for people with arthritis; and we conducted a half-day policy seminar on the specific information and education needs that could run alongside personal health budgets to inform our thinking and policy development.

People with arthritis perceived one of the main benefits of personal health budgets would be to give them more control of their health condition: this view was expressed by a large majority (77%) of our survey respondents. Many thought that with a personal health budget they would have more choice of specific services and therapies they considered would improve their health. They believed that personal health budgets had the potential to be empowering and could produce a more collaborative approach to healthcare. However they were concerned about health professionals' willingness to share decision-making.

Over half of our survey respondents were concerned that personal health budgets would reduce their access to traditional services. There were also concerns raised during our research about the potential bureaucracy and the affordability of personal health budgets in a time when the NHS is trying to make considerable savings.

Both health professionals and people with arthritis recognised how important it was to ensure that each individual's care plan was tailored to them, but they foresaw particular challenges for people with arthritis due to the fluctuating nature of the condition. Planning 'in the good times' would be necessary for contingencies 'in the bad times' and specialist input about the nature of the condition and its likely progression would be needed as the care plan was being developed.

If personal health budgets do become widely available on the NHS then Arthritis Research UK would like to make the following recommendations:

Recommendation one:

Those involved in care planning for people with arthritis should take account of the nature and impact of arthritis, in particular allowing for contingencies during exacerbations and for regular reviews.

Most people living with arthritis will experience fluctuations in the severity of their condition, including occasions when their symptoms will flare up. Flares can begin without warning, and their duration and severity is unpredictable.

During a flare, people may not be well enough to return to their health professional to negotiate new budget requirements, and therefore the possibility of flares must be included in the initial plan for the year ahead.

Since specialist knowledge about the likely course of a condition or possible side effects of treatments might be needed to set out a care plan for someone with arthritis, it will be necessary to facilitate input from specialist care (such as rheumatology) into the planning process.

Recommendation two:

All health professionals involved in care planning and supporting people with common long term conditions should be alert to the presence of arthritis as a major comorbidity that must be taken into account in discussions about personal health budgets as part of the overall process to meet individual needs.

Arthritis is a very common condition and many people whose health needs focus on a different condition will also have needs relating to the pain and disability of arthritis.

Pain and physical disability are major contributors to overall health and wellbeing. If arthritis is overlooked, a substantial opportunity is lost for people to improve their quality of life.

There are National Institute for Health and Clinical Excellence (NICE) clinical guidelines for both rheumatoid arthritis and osteoarthritis. Health professionals involved in care planning for people with arthritis, whether or not it is their primary condition, must be aware of these guidelines, and the recommendations they contain, to adequately support budget holders with their planning.

Recommendation three:

A range of options and/or case studies should be developed for potential personal health budget holders, with an explanation that these represent illustrative, but not exclusive, choices.

Starting with a blank sheet of paper when composing a care plan and planning how to spend a budget can be challenging. People with arthritis would benefit from being able to review a range of options illustrating how they could use their budget to address their health needs.

Useful resources could include examples of the types of therapies that have been shown to be helpful, approaches that others with similar conditions have taken, and directories of local services that people can approach.

Over time as people gain confidence in the care planning process, people are likely to need such resources less, but may be able to contribute their own experience to support others who are embarking on this for the first time.

Recommendation four:

Training about personal health budgets should be routinely offered as part of Continuing Professional Development for health professionals.

Training to equip professionals to move from a traditional model of giving instructions and solutions within a framework of clinical decision making to giving explanations and information in the setting of shared decision making would be required.

Health professionals would need training on three levels:

- » core information about the mechanism of personal health budgets
- » training to support adoption of the cultural change needed for the changing relationship between health professional and patient
- » appropriate condition-specific knowledge to enable workable care plans to be adequately created.

To ensure consistency, good understanding and appropriate allowance for training time required, content on personal health budgets should be required as part of the undergraduate and postgraduate curriculum in clinical training and should be routinely offered as part of continuous professional development. The area should be re-visited in increasing complexity as training progresses.

Local training will also be required to ensure that professionals advising on care plans are fully aware of the rules governing personal health budgets in their area.

Recommendation five:

The supportive role of third sector organisations needs to be properly described so that it can be harnessed appropriately and effectively; and adequate additional funding will need to be identified and cannot be assumed.

National arthritis and other musculoskeletal charities represent an important resource in relation to personal health budgets. Charities could have an important role in raising awareness about the nature and implications of personal health budgets, could play a valuable role providing mentorship and brokerage, and could potentially act in a monitoring capacity to feedback experience to DH and the NHS.

However, the increased demand of delivering additional information and personalised support for personal health budgets may place a strain on resources and there is insufficient clarity about how the necessary funding would be found.

2. PERSONAL HEALTH BUDGETS

Personal health budgets are part of a wider drive to personalise health and social care which dates back to the 1970s, when disability groups started campaigning for people to have more control over the money that was being spent on their needs.

Personal health budgets build on experience in social care and personalised care planning for people with long term conditions (LTCs), and aim to give them more choice and control over the services and care they receive. A personal health budget can allow people to choose to do things differently, tailoring services closely to needs.

How do personal health budgets work?*

What is a care plan?

At the heart of a personal health budget is a care plan. This helps people with a long term condition or disability, to set out their healthcare and wellbeing needs, the health outcomes they want, the amount of money in the budget and how this will be spent. Care plans are developed by people with long term conditions in partnership with their health professional and along with input and support from voluntary or community organisations. The plan must then be signed off by the person's local NHS team.

People who take up the offer of a personal health budget agree to receive a direct sum of money each year – an amount that otherwise would have been spent on them by the NHS. Together with their healthcare team, people agree their anticipated health needs for the year ahead and develop a care plan: how to use their budget to meet these needs. This can include buying personal equipment, paying for carers or trying complementary therapies that may not be routinely available on the NHS. For example, someone with a musculoskeletal condition may choose to use hydrotherapy. **Treatments provided directly by doctors, such as medication or operations, are not included in this scheme.**

People can spend the money themselves or nominate someone to manage the budget on their behalf, such as a broker. The scheme recognises that, while health professionals are clinical experts, people with long term conditions will often be experts in how their condition affects them and what works for them.

Piloting and evaluation

The DH has been piloting this new way of arranging care throughout England focusing on conditions such as diabetes, chronic obstructive pulmonary disease (COPD), stroke, neurological conditions and mental health. During the pilot programme, the NHS has been considering how to set a budget, how to support people through the process of setting and living with a budget, and how to develop the market of products and services people can choose from to enable real choice.

Arthritis and other musculoskeletal conditions were not selected as a focus of any of the centres in the initial personal health budget pilot scheme**. Hence, to ensure the needs of people with musculoskeletal conditions were recognised we undertook a number of research activities to feed into this process. The independent evaluation of the personal health budget pilot scheme is being conducted by a partnership between existing research teams at three institutions led by the Personal Social Services Research Unit (PSSRU) at the University of Kent. There have been a number of interim reports, and the final report on the evaluation is anticipated in October 2012.^{1,2,3,4,5}

* Further information on personal health budgets is available at www.dh.gov.uk/personalhealthbudgets.

** The fourth interim report recognised that there were participants in the personal health budgets pilots who had co-morbidities including arthritis, osteoporosis and back and joint pains.

Policy context

*'Experience from the implementation of personal budgets in social care underlines the importance of budget holders having sufficient information to make decisions'*⁶

*'Ensuring that everyone who wants support in using an individual budget has that support is critical.'*⁷

In its June 2011 report to government on the future for NHS modernisation⁸, the NHS Future Forum recommended that within five years all those patients who would benefit from a personal health budget should be offered one. The Government committed that, subject to evidence from the pilots, the Secretary of State's mandate to the NHS Commissioning Board would 'make it a priority to extend personal health budgets, including integrated budgets across health and social care'⁹. The aim over the long term would be to introduce a right to a personal health budget for people who would benefit from them.

As a step towards achieving this, on 4 October 2011 the Secretary of State announced that, subject to the evaluation, by April 2014 everyone in receipt of NHS Continuing Healthcare* would have a right to ask for a personal health budget, including for a direct payment. In addition, Clinical Commissioning Groups would be able to offer them more widely on a voluntary basis.

Policy research in LTCs has shown the need for good information for those using personal budgets and the need for adequate training for those responsible for administering them and advising people with long term conditions. Equally, approaches including the Wagner Chronic Care Model indicate that for people with long term conditions such as arthritis, 'the best outcomes are achieved when three components of care are integrated;

- » a prepared proactive practice team
- » informed engagement by people in their own care
- » partnership working between health professionals and people with LTCs.¹⁰

* 'NHS continuing healthcare' is care provided over an extended period of time to meet physical or mental health needs that have arisen as a result of disability, an accident or illness. It can be provided in a variety of settings including a hospital, nursing home, hospice or the patient's own home. For further information see: www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Continuingcare/index.htm

3. ARTHRITIS AND OTHER MUSCULOSKELETAL CONDITIONS

Arthritis and other musculoskeletal conditions are disorders of the joints, bones and muscles – including back pain – along with rarer but serious systemic autoimmune diseases such as lupus. Together, these conditions affect around ten million people across the UK and account for the fourth largest NHS programme budget spend¹¹ of £5 billion in England¹². Arthritis is the biggest cause of pain and disability in the UK and with other musculoskeletal conditions accounts for 20% of patients consulting with their GP¹³. It is clear that these health conditions have a considerable impact on people's lives.

By far the most common form of arthritis is osteoarthritis affecting an estimated eight million people. Osteoarthritis usually affects people over 45, with pain and loss of movement being the main symptoms. Much of the care for osteoarthritis is delivered in the community, either in GP surgeries or as outpatient appointments.

Another common form of arthritis is rheumatoid arthritis, which affects around 400,000 people in the UK¹⁴. Rheumatoid arthritis is a disorder where the immune system attacks the joints, causing them to become inflamed, and is the most common form of inflammatory arthritis.

Once established, both osteoarthritis and rheumatoid arthritis are life-long conditions causing pain and disability. The risk of developing a musculoskeletal condition increases with age and so the ageing population represents a growing challenge.

'Since being diagnosed with rheumatoid arthritis four years ago my life has changed beyond all recognition – but one of the difficulties I face is that on the outside I still look to everyone else the same as I would have done five years ago. The other main problem is the variability of my condition. Some days I have been able to do 'normal' things, but sometimes even the most simple task like a supermarket shop feels like how I imagine running a marathon must feel.

This makes it very difficult to plan – I am permanently nervous about making commitments that I don't know I can keep – and it is one of the main reasons why I am now on long term sick leave from the job I loved. The emotional side of having a musculoskeletal condition such as rheumatoid arthritis is, in my opinion, also much ignored. I have found the loss of my career and previous lifestyle very hard to come to terms with and have been treated for depression.

Overall my condition is constantly changing, as is the way in which I and those around me are able to cope with it.'

– Eleanor Goddard, person with rheumatoid arthritis speaking at the policy seminar

It is also important to recognise the impact and interactions of co-morbidities on people's health. A substantial number of people with another long term condition, such as hypertension or heart disease will also have osteoarthritis¹⁵. The pain and disability of osteoarthritis may well have an equal or greater impact on their quality of life than the disorder for which they are 'being seen' by a health professional.

4. METHODOLOGY

Each of the twenty sites selected by the DH for the personal health budget pilot set out a particular objective and focus (e.g. the Medway pilot focuses on people with a neurological condition, COPD, dementia or those who have had a stroke)*. None of the DH pilot sites has focused explicitly on people with arthritis or other musculoskeletal conditions. To initiate development of an evidence base in this area, Arthritis Research UK therefore undertook three related activities to explore the potential implications of personal health budgets for this group of people:

- » We invited people with arthritis and other musculoskeletal conditions to respond to a survey, which was distributed on the Arthritis Research UK website and via members of the Arthritis and Musculoskeletal Alliance (ARMA), Age UK and the Patients' Association.
- » We held a one-day workshop at the DH, to which the survey respondents were invited alongside clinicians, representatives of third sector organisations, personal health budget pilot sites leads and DH policy and delivery teams.
- » We held a half-day policy seminar to explore in more depth with stakeholders from health and social care the steps that might need to be taken to help ensure successful outcomes for people with musculoskeletal conditions holding a personal health budget from an information and educational needs perspective.

The combination of survey, workshop and seminar approaches has provided quantitative data supported by qualitative information to add depth and detail to aspects of the discussion. This report contains findings from all three pieces of work and recommendations based on those outputs, particularly focused on how personal health budgets may affect people with arthritis.

This report is intended for policy makers – especially those considering the evaluation of the personal health budget pilot – national and local government, health, allied health, and associate health professionals, Parliamentarians, patient advocates, charities as well as the wider public, particularly those with an interest in arthritis and musculoskeletal health and health and social care design.

Details of the methodology and participants may be found in the Appendices.

* For detail on the pilot sites see <http://www.personalhealthbudgets.dh.gov.uk/About/aboutPilots/Map/>

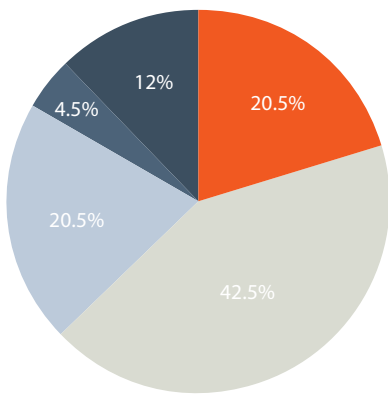
5. ATTITUDES TO PERSONAL HEALTH BUDGETS

Our research examined how personal health budgets were perceived and how they could be used by people with arthritis who responded to our survey and by patients, clinicians, charities, managers and other health professionals who engaged in our workshop and policy seminar.

After the concept of a personal health budget was explained, 63% of respondents to our survey said they would accept a personal health budget if offered – but 25% said they would not (see figure 1).

Figure 1: Responses from participants in our survey when asked if they would accept a personal health budget.

■ 20.5% Definitely would
 ■ 42.5% Probably would
 ■ 20.5% Probably would not
■ 4.5% Definitely would not
 ■ 12% Not stated



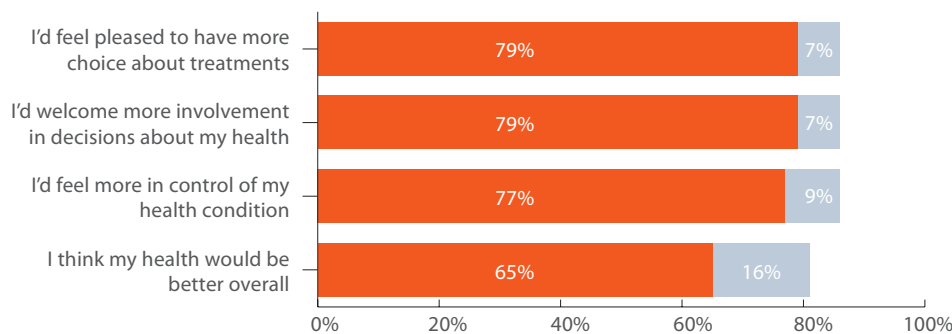
Perceived benefits

A large majority (77%) of survey respondents said having a personal health budget would make them feel more in control of their health condition, with 9% disagreeing (See figure 2). The general view of those surveyed was that they would be pleased to have more choice about the services available to them and would welcome the chance to have more involvement in decisions about their health. Most felt that their health would then be better overall.

53% of respondents said they thought personal health budgets could enable them to have more choice of treatments and services that are not available on the NHS.

Figure 2: Responses from participants in our survey when asked to agree or disagree with a series of statements about personal health budgets.

■ Agree
 ■ Disagree



People with arthritis and other musculoskeletal conditions at our workshop made a number of suggestions about how a personal health budget could be used:

- » physical symptom control, such as via hydrotherapy or reflexology
- » lifestyle management, such as Tai Chi or weight loss help
- » mental health support, for example through laughter workshops or meditation
- » wider support, such as employment advice or help with child care.

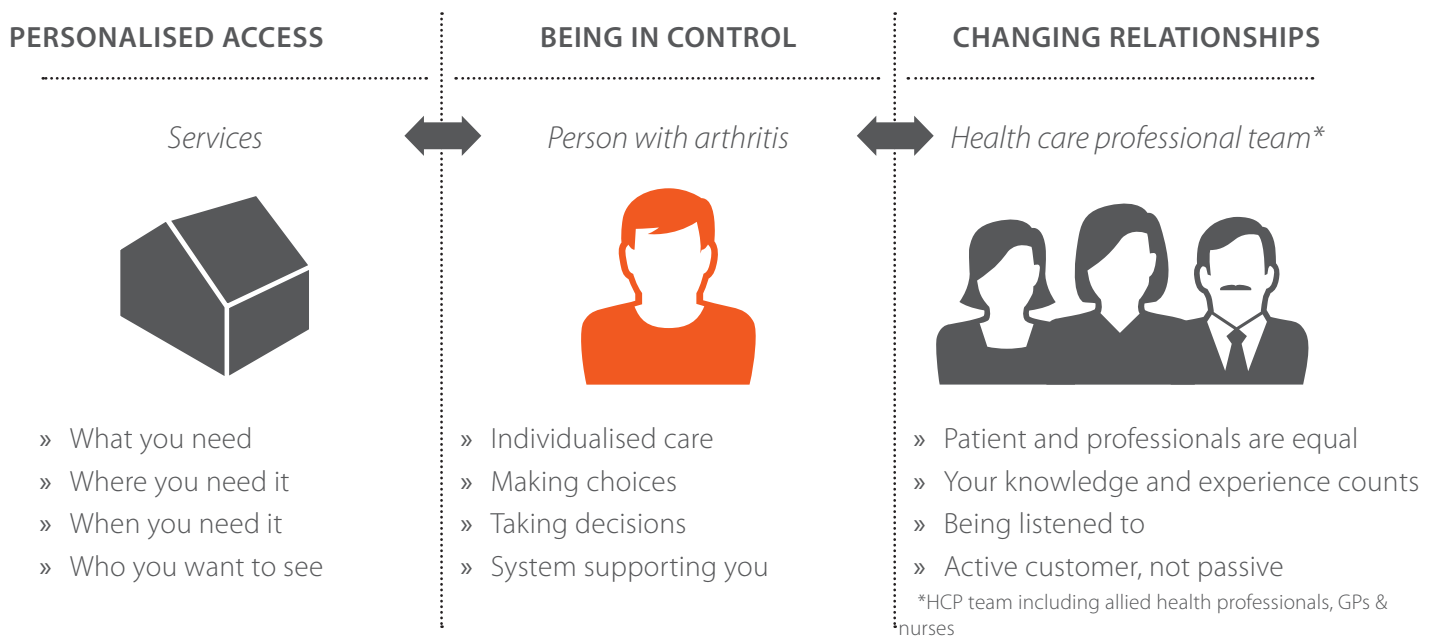
We further explored the potential of personal health budgets in our qualitative work, where four broad themes emerged around perceived benefits (see figure 3):

- » **Empowerment:** giving the sense of ‘being in control’: people with a long term condition no longer having to feel humble or grateful for whatever they were given, but rather having a legitimate right/entitlement to access things which work for them.
- » **Providing access to different treatments or services:** people with arthritis having access to complementary therapies (outside the set ‘courses’ currently available in some areas such as additional physiotherapy).
- » **A collaborative approach to healthcare:** changing people’s relationship with health professionals. Giving them the sense of empowerment – of being seen as a customer, not a recipient.
- » **Enabling an integrated holistic approach:** eliminating the need to repeat oneself, and having better continuity of information flows and services.

Figure 3: Holistic approach to health care

All your needs can be taken into account:

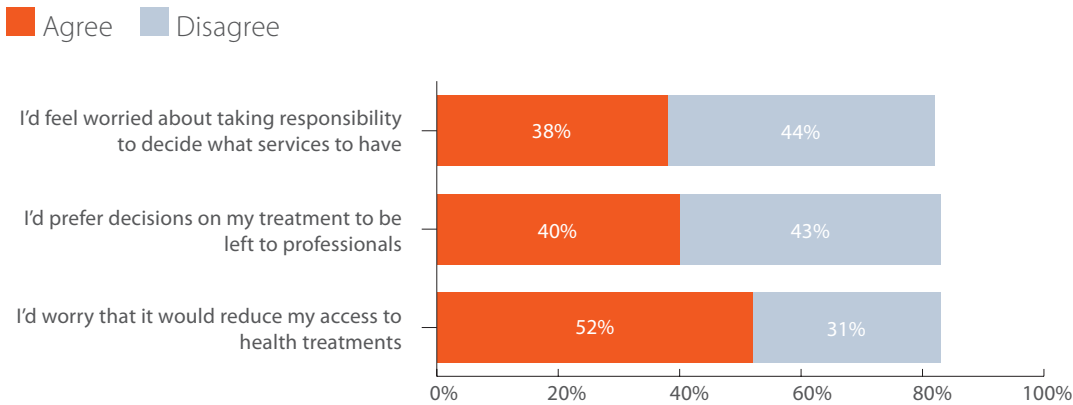
- » Timing and location of care built around your needs
 - » All information centred around you
 - » Treating your needs, not your condition.



Perceived risks and concerns

Over half (52%) of our survey respondents said that they would be worried that personal health budgets would reduce their access to treatments; 31% disagreed with this and 17% said they did not know. Some two-fifths (38%) said they would feel worried about taking responsibility to decide what services to have and a similar number (40%) said they would prefer decisions on their treatment to be left to health professionals (see figure 4).

Figure 4: Responses from participants in our survey when asked to agree or disagree with a series of statements about personal health budgets.



We explored the potential of personal health budgets in our qualitative work. From round table discussions a number of concerns emerged:

- » **Information and support:** What reliable and useful information will be available? What support such as brokerage services will be available and will the quality of service be dependent on what is available locally? How do you regulate to ensure quality and safety amongst the many available providers?
- » **Care planning approach:** A care planning approach is a new way of working. Will medical practitioners be willing to engage in a collaborative approach? Will they be able to achieve the necessary culture change to deliver new ways of working?
- » **Finance:** A personal health budget involves direct payments: this may not be suitable for everyone. Some people may not have the confidence or ability to manage their own budget. Will there be a risk of financial fraud?
- » **Impact on health system:** What could be the potential impacts of personal health budgets on the wider health system? Could this lead to NHS funds being spent on discredited therapies? Could this lead to some services becoming unviable and decommissioned? Could this lead to a postcode lottery? Are they viable in an NHS which is seeking to make efficiency savings?
- » **Bureaucracy:** Professionals with experience of personal budgets in social care warned of the risk of excessive bureaucracy, where the cost of administering and checking could even outweigh the cost of the items being discussed. Would the cost of the paper trail engendered by direct payments be proportionate to achieve the accountability for which it was being designed? Would these extra costs be affordable within a system that was already under severe budget pressure?
- » **Challenge to integration of care:** Given the potential for a wider range of providers to become involved in an individual's care under a personal health budgets scheme, could there be a risk of communications failures and an incomplete or fragmented record of a person's care? Could technology solutions, such as providing the patient with a memory stick on which data from all providers could be recorded, potentially overcome this?
- » **Perceived rationing:** People with arthritis worried that their assessed sum of money might be lower under the personal health budget regime than it was at present. Health professionals too were concerned that, in the current climate where the NHS has to make considerable savings, they could mistakenly be seen as responsible for cutting budgets. Reassurance that the introduction of personal health budgets does not represent a means of rationing looks likely to be important.

- » **Resource use:** High quality care planning for people with arthritis, including people who have arthritis as a co-morbidity alongside other conditions, is likely to identify substantial unmet need. Meeting this need could produce pressure on resources at a time of austerity. Others felt that personal health budgets could reduce the stretch on services, as people would access them less if they were able to develop more personalised approaches to their health.

Overall

Most people who took part in our survey would welcome the opportunity to manage their own personal health budget. It is clear that not everyone with arthritis feels that personal health budgets are best for them and it is important that no one is compelled to accept one.



6. REFLECTING THE NEEDS OF PEOPLE WITH ARTHRITIS AND ITS IMPACT

Arthritis and other musculoskeletal conditions are a broad group of conditions (see section three for an overview). Patients with these types of conditions often experience fluctuations in the severity and impact, and this means there is an important need to 'plan for the bad times in the good times'.

The most common type of arthritis is osteoarthritis. A substantial proportion of people with a long term condition will also have osteoarthritis and thus a model of care is needed which recognises the impact and interactions of musculoskeletal co-morbidities on people's health.

6.1 Care planning approach

A care plan forms the heart of a personal health budget and it was important to understand how people with arthritis, and those involved with their care, felt about care planning. However, recent data indicates that the majority of people with arthritis do not currently have a care plan.

The clinical NICE guideline for osteoarthritis recommends co-development of a management plan between patient and clinician¹⁶. However, recent research by Arthritis Care has found that only 18% of people with osteoarthritis currently have an agreed care plan¹⁷.

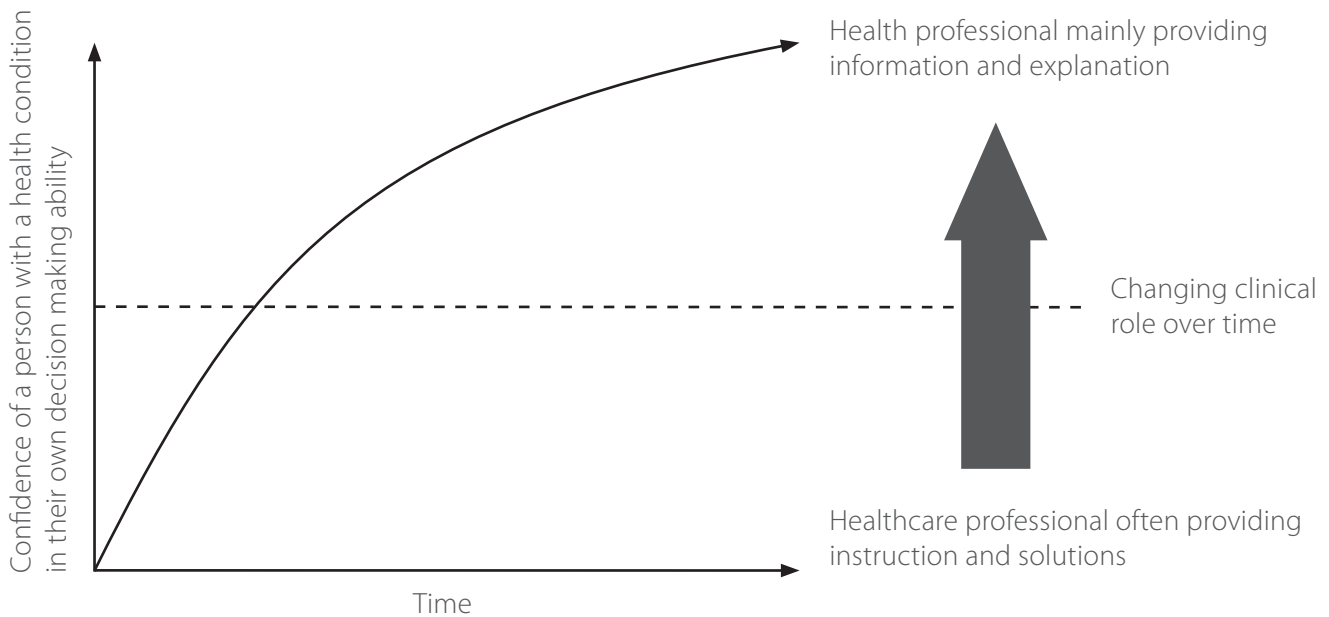
In fact, for many people with arthritis the focus of their care planning may be more concentrated on their co-morbid conditions such as their diabetes, COPD or heart disease rather than their arthritis. In these cases, it is important to ensure their musculoskeletal health is considered because the pain and disability of their osteoarthritis may typically have an equal or greater impact on their quality of life, especially the ability to remain physically active, as the apparent primary condition.

In common with other groups which have considered care planning, a central theme emerging was that it should be individual and holistic. Feedback from health professionals who had been involved in pilot programmes testified to the value of the care planning process itself. They also indicated that people with long term conditions grow in confidence about the care planning process over time, but initially many would find they needed a high level of support from health professionals. It is therefore critical that health professionals have the knowledge and skills to engage in the process and to support people and help them develop their own skills.

With growing confidence in their own decision-making ability over time, people with arthritis can benefit from a different type of relationship with their clinicians, one which is based more on partnership and problem solving. At the same time, our survey revealed that personal health budgets are not everyone's preference and we would advocate that no one should be compelled to take one if they do not wish it.

Those tailoring care plans and personal health budgets to the needs of people with arthritis must recognise that as confidence in the care planning and personal budgeting processes changes over time, the role of the health professional will also shift (see figure 5).

Figure 5: Changing relationship between a health professional and a person with arthritis after introduction of care planning and personal health budget.



Given the fact that care planning will generally take place in a primary care setting, research is needed to find out what primary care health professionals already know about personal health budgets. This work should identify the knowledge, skills and attitudes that make up the required competencies needed to carry out this work. More needs to be understood about the minimum necessary core degree of knowledge for specific, very common health conditions – such as arthritis – to enable this to be done effectively.

In addition, specialist knowledge about the likely course of a condition or possible side effects of treatments will be required to set out a care plan for those with severe forms of arthritis. Since this is likely to come from rheumatologists, who often work in hospitals, it was acknowledged that it would be helpful to facilitate input from secondary care into the planning process.

6.2 Fluctuating conditions: flexibility is needed

The fluctuating nature of arthritis and other musculoskeletal conditions provides a particular challenge for the development of personal health budgets. As one person with arthritis in our policy seminar said:

‘When the condition is in remission, I feel that some therapies are unnecessary – even though I know I appreciate them when I have a flare-up. It could be difficult to work out an appropriate care plan on your own because of swings like this.’ – person with rheumatoid arthritis

It was clear that generic plans based on knowledge of ‘the average case’ is not appropriate to the management of arthritis because people with the same condition did not necessarily have the same needs, and indeed these might vary considerably.

There was also recognition of the need for specialist input (such as from rheumatologists who work in specialist care) about the severity of the conditions, likely progression and the need for concrete suggestions about how flare-ups could be managed. Such suggestions could form useful building blocks of a care plan.

The presence of other health conditions would be likely to affect an individual’s requirements for their arthritis. Likewise, the presence of arthritis and musculoskeletal conditions will affect requirements for people with a

personal health budget for other conditions. An analysis of personal health budget holders in pilot sites showed a large number of people on the pilot had co-morbidities¹⁸:

*'Many interviewees had additional health problems, including arthritis, osteoporosis, back and joint problems, angina and high blood pressure; these were sometimes as significant as their personal health budget condition.'*¹⁹

6.3 Interventions used by people with arthritis

People with arthritis at our workshop commented that a personal health budget could enable them to benefit from interventions which may be limited, or not normally available, on the NHS. For example, individuals may choose to use their budget to provide more physiotherapy sessions than would normally be supplied through the NHS.

In our survey, 74% of respondents had spent their own money on interventions they considered contributed to their healthcare for their arthritis and other musculoskeletal condition over the last 12 months. The most common items purchased were diet and nutritional supplements, equipment to 'help you do every-day things', and massage.

The most commonly purchased equipment were kitchen items: such as jar openers, walking aids, sticks or frames; physical or joint supports; and bathroom items, such as shower rails or lever taps.

It is clear that equipment which has previously been provided as part of the social care remit could fall under the domain of personal health budgets in the future. In the longer term, there may also be potential for closer integration of healthcare and social care budgets.

Increasing flexibility and patient choice could also introduce new challenges for clinicians in their role in advising patients, particularly for interventions which people with arthritis have found from experience to improve their quality of life, but where clear medical benefit has not been scientifically established.

Arthritis Research UK's 2009 'Complementary and alternative medicines for the treatment of rheumatoid arthritis, osteoarthritis and fibromyalgia' report, is an evidence-based review of the use of complementary and alternative medicines for arthritis and musculoskeletal conditions. Using evidence from randomised controlled trials, it aims to inform and support people with arthritis or fibromyalgia about the use of complementary medicines. The report does differentiate between absence of evidence from evidence showing no benefit. In many cases, it indicates that there is limited scientific evidence of effectiveness of such treatments²⁰.

While recognising that some non-traditional services could benefit individuals with musculoskeletal conditions, health professionals in our DH workshop and policy seminar were cautious about seeing some complementary and alternative medicine approaches become available through personal health budget provisions in the absence of evidence of their effectiveness.

When a care plan is designed by a patient and a health professional, it is vital that the patient is informed about what the evidence base demonstrates about the efficacy and safety of interventions they are considering using. Please see section eight for discussion of the issues this raises for professional training.

Recommendation one:

Those involved in care planning for people with arthritis should take account of the nature and impact of arthritis, in particular allowing for contingencies during exacerbations and for regular reviews.

Recommendation two:

All health professionals involved in care planning and supporting people with common long term conditions should be alert to the presence of arthritis as a major comorbidity that must be taken into account in discussions about personal health budgets as part of the overall process to meet individual needs.

7. INFORMATION TO EMPOWER DECISION-MAKING

For people with arthritis, the principal concern was that they had access to the information, support and advice that they needed. They felt that information should be understandable, accessible and timely. It was expected that basic information about personal health budgets would be available online*, but this would need to be supplemented especially for those who did not have either access to, or the ability to use, on-line resources.

Beyond general material about the concept, people wanted an explanation on the sorts of services and facilities available locally that they could spend their money on such as directories. It was important that the information was reliable but there was not a consensus over which types of information definitely should or should not be accredited (See figure 6).

7.1 Finance

A theme emerging from our work was that information on the finance available and the rules governing its expenditure should be clear and be provided up-front. This has also been reflected in the feedback from the DH pilot sites²¹. It is crucial that people are aware from the start what their budget is: this will be a key priority for information provision locally and for effective implementation.

It was recognised that there would inevitably be rules to deal with certain contingencies. For example, if a budget were under-spent in one year – perhaps due to a period of prolonged good health – could it be carried over to the next? What happened if a person's condition deteriorated substantially during a budget year – what scope was there for reviewing the budget and how often? Would 'over treatment' be encouraged if people feel they must spend their budget? It was imperative that all such rules should be made clear before the care plan was embarked on.

An emerging theme was the potential impact of personal health budgets on NHS services. The NHS is undergoing a period where cost savings need to be identified and it is not clear what additional costs implementing personal health budgets beyond the pilot sites, alongside widening the eligibility criteria, would have. This is an area where further clarity is needed.

7.2 Menus and case studies

Our research showed that, as well as the basic information provided online about what personal health budgets are, there may be a role for some printed information, such as leaflets. These were needed to provide a roadmap so that people are better informed about the nature of the process and understand the choices they may need to make.

Attendees at the policy workshop discussed the possibility of materials setting out a range of options for how people with arthritis could spend their personal health budget. It was generally agreed that, compared to the 'blank sheet of paper', the pro-active presentation of the range of options for how people could spend their personal health budget would be helpful for two reasons. First, it would illustrate the type of creativity and opportunity possible. A blank piece of paper is a difficult place to start and so this could support people to identify effective approaches to supporting their own health. Second, if done at a local level, this would relate directly to the types of service that were actually available nearby. Further feedback suggested that case studies could be useful, showing how others with particular conditions had spent their budget in the past, and even illustrating what was not acceptable.

The caveat, however, was that a definitive menu could be seen as too restrictive. One of the intentions of personal health budgets was to open up to people choices that might not otherwise be made. Participants were keen to stress that the options presented on a menu did not preclude other potential choices.

* DH is developing a toolkit on personal health budgets for its learning network; the People Hub group has also developed a website about personal health budgets.

Figure 6: Information needs of personal budget holders

| Types of information | Sources of support | | | |
|----------------------------------------------------------------------------------------------------------|---------------------------------------------|----------------------------------------|----------------------------------------------------------------------|--------------------|
| Choice of budget components » Menu » Local directories » Case studies | Peer Support (including national charities) | Skilled, informed health professionals | Authoritative information (printed & electronic) e.g. from charities | Brokerage services |
| Evidence of value & benefit » Evidence - based costs » Outcomes » Patient experience | | | | |
| Financial management » Rules for spending » Total value of budget » Liabilities | | | | |

As one health professional explained, in relation to her experience at a pilot site:

'[Some] patients have requested... attend[ing] a commercial slimming clinic, to reduce their weight and the pain in their knees. While this might not be on a 'menu of options', it illustrates the importance of treating a menu like this only as an indication of what's available, not a comprehensive list.'

– Continuing Complex Care Manager, personal health budget pilot site.

Feedback from the pilot sites illustrated there was demand amongst both patients and health professionals for information about how personal health budgets work. The potential transition from pilot sites to a wider roll out means there could be a new and greater demand for information about the core basics of personal health budgets. Educational tools for health professionals will need to be widely distributed to engender an understanding of this new approach in healthcare.

If personal health budgets are implemented more widely, then it is important that peer-to-peer learning is enabled between those who have set up personal budget programmes and those who are implementing them for the first time. For example, when considering information needs for budget holders, the pilot sites have already generated substantial experience and learning as to what works. This must be harnessed to support new implementers in identifying information and support needs for personal budget holders in their area. This will build on the work already done through the on-line forum of the personal health budgets learning network.

Information for personal health budget holders needs to be produced at both national and local level. To avoid unnecessary duplication, national and local information resources should be mapped and signposted through NHS websites, such as NHS Choices. This will ensure people have the most reliable and useful information they require to manage their budget.

Whereas some information should be produced nationally, other types of information should be more locally focussed:

- » **Generic national information:** how do personal health budgets work?
- » **National or local:** how could personal health budgets be spent? E.g. case-studies.
- » **Local:** what services and facilities can personal health budgets be spent on locally? E.g. directory of services.

See section eight for further discussion of the role of charities.

Recommendation three:

A range of options and/or case studies should be developed for potential personal health budget holders, with an explanation that these represent illustrative, but not exclusive, choices.



8. DEVELOPING SUPPORTIVE INFRASTRUCTURE

People with arthritis felt strongly that it was important for there to be sufficient support available to help them both with the choices about the components of their care plan and with an understanding of the financial implications. There is a clear role for supportive systems to enable people to navigate around services and to help signpost how to best spend their budget. For this to be fully realised it is clear that a range of professionals will require training to provide the necessary level of support.

As a report from the University of Birmingham Health Services Management Centre, and the Centre for Welfare Reform has noted about individual budgets in social care, *'The success of individual budgets depends on all the relevant actors being engaged – users, professionals, carers, local authority and NHS commissioners and the voluntary sector.'*^{22'}

8.1 Education and training for health professionals

For health professionals to be able to deliver this support effectively, they will require additional knowledge and skills. There are three levels in terms of training needs:

- » core information about the mechanism of personal health budgets
- » training to support adoption of the cultural change needed for the changing relationship between health professional and patient
- » appropriate condition-specific knowledge to enable workable care plans to be adequately created.

All health professionals providing treatment for people with a personal health budget should be familiar with the basic principles and workings of the system. The overall knowledge requirements for this should be set nationally. The details and rules governing personal health budgets may vary between commissioning areas. Local training will therefore be needed for health professionals directly involved in supporting people in developing their personal health budget. This should include the local administration, implementation and governance, alongside rules that apply in that area. This bears out the findings of the Health Foundation which conducted a research scan of the evidence base for personal health budgets and noted that *'Both central Government leadership and local leadership, alongside training and support for staff is needed.'*^{23'}

To ensure consistency, good understanding and appropriate allowance for training time required, content on personal health budgets should be required as part of the undergraduate and postgraduate curriculum in clinical training and should be routinely offered as part of continuous professional development. The area should be re-visited in increasing complexity as training progresses. It should build on the wide knowledge about personal budgets that already exists in the social care setting, but much of which has not yet crossed into the health budgets arena.

A number of sources could be drawn upon to provide the breadth of education and training outlined above. Whether training is formally accredited or not, it was thought essential that minimum standards were set for the quality of training to meet.

Personal health budgets imply not only a technical change in how care is delivered, but represent a new approach to the clinical relationship. Training for health professionals will therefore be required on the consultation style appropriate to personal health budgets. From a traditional model of giving instructions and solutions within a framework of clinical decision making, health professionals would need to learn to give explanations and information in the setting of shared decision making. There should be particular emphasis on the conversation between the person with arthritis and health professional about the evidence base and about how interventions may make the person feel.

As a specialist rheumatology nurse from one of the pilot sites put it:

'I feel that nurses will find their role as patients' advocates more challenging under a personal health budgets system, because in advising on which services to include they will need to balance their clinical knowledge with patients' preferences – and these may not always match. In such circumstances, it is nurses' duty to ensure that patients' decisions are properly informed.'

8.2 Brokers

Some of the managers from pilot projects described the use of local brokers, who had both helped in the construction of care plans and had managed the financial flows in the system. For example, in the Nottingham personal health budget pilot, four external brokers had worked with health professionals and individuals to support the development of care plans. It was clear that this was a resource-intensive process, and could potentially be both an expensive route to follow and generate conflicts of interest.

In comparison, personal health budgets (or *persoonsgebonden budget* or PGB) have existed in the Netherlands since 1996²⁴. PGBs have since become so popular that the Dutch government has tightened its eligibility criteria, owing to the demand and an overspend in this budget area. It has also had to introduce a voluntary code of practice for agencies acting as 'brokers' and to prohibit direct payments to such agencies. Much can be learned from other experiences of personal health budget programmes.

8.3 The role of charities

In the same way that the Audit Commission found that charities could and should play an important role in the delivery of individual budgets in social care²⁵, our work highlighted that national charities represent an important resource in relation to personal health budgets. For example, some charities concerned with arthritis such as Arthritis Care and the National Rheumatoid Arthritis Society, already provide training on self-management. It may be appropriate for charities to provide training in the area of personal health budgets. Charities could have an important role in raising awareness about the possibility and nature of personal health budgets, which may be particularly important given that public knowledge about the scheme is currently at a relatively low level. They could also play a valuable role as mentors and advocates, and perhaps in a monitoring capacity to feedback experience to DH/NHS, perhaps via local HealthWatch organisations.

The introduction of personal health budgets could also provide a welcome catalyst to encourage health professionals to share more information with patients about the types of services that voluntary organisations can offer.

However, there was concern about the strain on resources that an increased demand on charities might place, with no clarity about how the necessary funding would be found to supply, for example, information, training and potentially individually tailored brokerage services.

Third-sector organisations were most concerned about the burden that the introduction of personal health budgets could inadvertently place on them, if this led to an increased demand for advice that they did not have the resources to provide. They wished to understand better the role that brokers had played in some of the pilots. Charities wanted to understand whether funding would be set aside to continue to provide information and resources of this sort if personal health budgets were rolled out further afield.

Recommendation four:

Training about personal health budgets should be routinely offered as part of Continuing Professional Development for health professionals.

Recommendation five:

The supportive role of third sector organisations needs to be properly described so that it can be harnessed appropriately and effectively; and adequate additional funding will need to be identified and cannot be assumed.

9. RECOMMENDATIONS

If personal health budgets do become more widely available on the NHS then Arthritis Research UK would like to make the following recommendations:

Recommendation one:

Those involved in care planning for people with arthritis should take account of the nature and impact of arthritis, in particular allowing for contingencies during exacerbations and for regular reviews.

Recommendation two:

All health professionals involved in care planning and supporting people with common long term conditions should be alert to the presence of arthritis as a major comorbidity that must be taken into account in discussions about personal health budgets as part of the overall process to meet individual needs.

Recommendation three:

A range of options and/or case studies should be developed for potential personal health budget holders, with an explanation that these represent illustrative, but not exclusive, choices.

Recommendation four:

Training about personal health budgets should be routinely offered as part of Continuing Professional Development for health professionals.

Recommendation five:

The supportive role of third sector organisations needs to be properly described so that it can be harnessed appropriately and effectively; and adequate additional funding will need to be identified and cannot be assumed.

APPENDIX I: THE SURVEY

Arthritis Research UK undertook three activities to inform our thinking and policy development on personal health budget.

i: Methodology

The survey was publicised widely to people with arthritis and other musculoskeletal conditions, through charities for people with musculoskeletal disorders, such as the National Rheumatoid Arthritis Society and Arthritis Research UK itself; through related charities, such as Age UK; and through the media. They were invited to complete a questionnaire, either in paper form or online at the Arthritis Research UK website. A total of 486 people responded in the period 15 August to 18 November 2011.

81% of respondents who disclosed their gender stated they were female and 19% male. 59% of the group who gave their age stated they were aged 55 or above and 41% under 55. 41% of respondents had rheumatoid arthritis, 25% osteoarthritis and 15% back pain as their main musculoskeletal or rheumatological condition. 9% had another inflammatory arthritis condition and 8% fibromyalgia. Of those who disclosed the severity of their condition, 43% described their condition as 'severe' and a similar number (47%) as 'moderate'. Only 10% described their symptoms as mild.

ii: Results

Most people who took part in the survey would welcome the opportunity to manage their own personal health budget. 63% said they would accept a personal health budget if offered – but 25% said they would not.

When the concept was explained, 53% of respondents said they thought personal health budgets could enable them to have treatments that are not available on the NHS and which they cannot afford now.

A large majority (77%) said having a personal health budget would make them feel more in control of their health condition, with only 9% disagreeing. The general view of those surveyed was that they would be pleased to have more choice about the services available to them and would welcome the chance to have more involvement in decisions about their health. Most felt that their health would then be better overall.

The services that people were typically paying for out of their own pockets included massage, physiotherapy and podiatry. Over one-third (35%) spent money on diet and nutritional supplements and 29% bought equipment to help them do everyday things. Around 10% of those surveyed said they spent their own money on herbal medicines, with a median spend of £45 per year.

Over half (52%) of the sample said that they would be worried that personal health budgets would reduce their access to treatments; 31% disagreed with this; and 17% said they did not know. Some two-fifths (38%) said they would feel worried about taking responsibility to decide what services to have and a similar number (40%) said they would prefer decisions on their treatment to be left to professionals.

While half (50%) of people surveyed said they felt they would be informed enough to make a decision about how to spend a personal health budget, nearly one in three (32%) disagreed.

The sources of help to which people with arthritis and other musculoskeletal conditions said they would want to turn were, in descending rank order:

- » health professionals.
- » people with the same or similar health conditions.
- » voluntary organisations.
- » the internet.
- » NHS sources.
- » friends and family.

APPENDIX II: THE ONE-DAY WORKSHOP

i: Methodology

The one-day workshop set out to explore personal health budgets and their potential for people with arthritis and other musculoskeletal conditions through the use of a series of facilitated group discussions. Participants included people with arthritis and other musculoskeletal conditions, health professionals, third sector organisations, personal health budget pilot sites leads and DH policy and delivery teams.

In particular, the aim was to assess the potential benefits and concerns associated with personal health budgets, and to identify how the risks could be overcome.

The day included:

- » An introduction to personal health budgets.
- » A keynote address given by Andrew Sanderson, Deputy Director, DH, on behalf of Paul Burstow, Minister of State for Care Services, which acknowledged the importance of partnership working, and set out the future direction for personal health budgets.

The day began with two discussions: firstly on how personal health budgets might be used, and on risks and concerns. Participants were then asked to select four main challenges on which to focus, and separate discussions were held on each, with the aim of addressing how the issues could be mitigated.

The four challenges chosen were:

- » How do personal health budgets sit with other personalisation initiatives and wider healthcare?
- » How to ensure that personal health budgets don't become overly bureaucratic?
- » How can we maintain joined-up services when people have personal health budgets?
- » The cost implications of personal health budgets.

At the end of the one-day workshop, attendees were divided into three different groups, according to their role, and were each asked to identify the main issues arising from personal health budgets that they perceived affecting them as a group.

ii: Main findings

Many people with musculoskeletal conditions were supportive of the concept of personal health budgets and thought of creative ways that a personal health budget could be spent to meet health needs. However, they and the health professionals expressed concern over how personal health budgets would work in practice and whether it would mean some people with long term conditions losing parts of their current care.

People with arthritis wanted health professionals to listen to them and to be involved in planning. The importance of advice and support to help them make decisions about their personal health budget was highlighted, but concerns were raised over how this would be provided and the knock-on effects on the third sector.

Personalisation

The group agreed that personal health budgets should not be seen as the only way to personalise healthcare, nor should they be seen as a stand-alone initiative separate from other NHS provision. Personal health budgets could enable better links with other services. For example:

- » A single coordinator, who was responsible for ensuring that different programmes/initiatives for a budget holders was joined up, could help to provide personalised care. This could be the person with whom the budget holder has the most contact – provided there was sufficient mutual trust, respect and understanding between them.

- » People with arthritis could have single assessments or reviews which bring all the right professionals around the table (some could be virtual, bringing in telehealth).

Bureaucracy

Ideas of how to reduce this included:

- » Developing an outcome-focused approach that reduced the need for recording everything.
- » Professionals to trust individuals more – people with arthritis do want to get well and stay out of hospital, and understand about not wasting money.
- » Pre-loaded cards were seen as a way of reducing the bureaucracy involved in direct payments.

Joined-up services

Suggestions to avoid duplication included:

- » Having a single plan containing all the information people with arthritis needed.
- » Having IT systems that share data (after appropriate consent has been received).
- » Budget holders being in control of their own data (in either hard copy or on a memory stick) that they could share with different providers, who could add information as needed.

Costs

Thoughts on reducing the cost burden of personal health budgets included:

- » Involving people with arthritis in decisions about what services should look like – need for local engagement.
- » Abolishing the division between primary and secondary care – so that cost savings and efficiency gains could be shared.

The insights from these discussions have been included throughout the report.

APPENDIX III: POLICY SEMINAR

i: Methodology

Arthritis Research UK held a seminar on 24 May 2012. Its purpose was to identify what type of information is likely to be required by people with arthritis and other musculoskeletal conditions if personal health budgets are introduced. It also considered the sort of education, training and support that may be needed – among health professionals as well as amongst patients – if their implementation is to be successful.

The seminar brought together some 40 people from a variety of backgrounds to inform the debate: health professionals and project managers working in the pilot areas for personal health budgets; people with arthritis and other musculoskeletal conditions; representatives of third sector organisations and professional associations concerned with arthritis and musculoskeletal disorders and other long term conditions; alongside other interested parties.

Chaired by Professor Alan Silman, Medical Director of Arthritis Research UK, the seminar was divided into two sessions: the first considered information needs, especially in relation to establishing a care plan, and the second focused on education, training and support. Each commenced with a series of short presentations from those with particular insight or expertise, followed by discussion among tables of around eight people, the outcomes of which were then shared with the whole room.

In the first set of discussions, delegates were asked to address three questions:

- » How should care planning work for arthritis and other musculoskeletal conditions? What could or should go into an arthritis care plan?
- » Should there be a role for 'menus of options' for different conditions?
- » What are the top five pieces of information that people with long-term conditions and health professionals would need to make personal health budgets work?

In the second round of discussions, the three questions concerned what sources of information and training were required for personal health budgets to work:

- » Should information/training come primarily from NHS/DH sources or should a wide range of sources be acceptable and, if so, should these be accredited?
- » Should information and training be provided (and thus vary) locally, or be standardised nationally?
- » What is the role for a) national charities and b) professional organisations in this process?

The insights from these discussions have been included throughout the report.

ii: Extracts from presentations

Eleanor Goddard, person with rheumatoid arthritis

'I was first diagnosed with rheumatoid arthritis in 2008. The variability and unpredictability of the condition makes care planning all the more complicated. When the condition is in remission, I feel that some therapies are unnecessary – even though I know I appreciate them when I have a flare-up. It could be difficult to work out an appropriate care plan on your own because of swings like this.

I think the therapeutic process of writing a care plan is going to be particularly helpful. I found it really useful to have time to talk to somebody about my condition, which helped me accept and come to terms with it and how it's going to impact my life.'

Jo Cumming, Head of Information and Helplines, Arthritis Care

'While Arthritis Care has not yet received specific enquiries about personal health budgets, I think lessons can be drawn from the questions that people ask our helpline operators about personal care plans in social services and

about self-management of their condition. Overall, people very much want to understand how to be able to take control of their condition.

Following the publication of our report on osteoarthritis, 'OA Nation', 95% of calls and emails we received were from people wanting information on pain management; 54% wanted information on how to exercise safely; and 38% asked for advice on diet, nutrition and weight management. Some wanted information on complementary or alternative therapies and others on self-management training courses. Once personal health budgets are introduced, people will need to know what's available – perhaps in 'menu' terms – and how to access it. But above all, they will need support to enable them to make a decision for themselves on what care will suit them best.'

Yvonne Fagg and Kirsty Freeman, Personal Health Budgets Team, NHS Tees Personal Health Budget Pilot

'In the early stages of our pilot, we commissioned an independent support planner to help develop care plans with service users. After a while, our own facilitators took over this responsibility. Their approach is to consult with patients and bring together everyone who the patient feels can and should contribute to their plan, for example their GP, nurse, carer or advocate.

To manage direct payments, we commissioned a local independent broker, who receives funding and organises expenditure on behalf of patients, in line with their care plan. We have found this to be essential, even though it's expensive.

We have found that people living with arthritis or chronic pain, as co-morbidities with other conditions, have often requested massage, TENS machines, hydrotherapy and physiotherapy as part of their care plan to help provide pain relief.'

Caroline Skevington, Continuing Care Complex Case Manager, Nottingham Personal Health Budget pilot

'Nurses' and other healthcare professionals' whole training has been about minimising risk and following clinical evidence, so it is culturally difficult for them to accept that patients should be allowed to opt for complementary or alternative therapies as part of their care plan. Training is necessary to help them overcome these inhibitions.

The clients themselves have found it valuable to work through a care plan methodically, and feel they have benefited by conducting that process.

Some patients have opted for personal assistants as part of their care plan, and we find they can add a great deal of flexibility to the way treatment is delivered, often saving time and increasing the quality of patients' lives. ... Another non-traditional service that patients have requested, is to attend a commercial slimming clinic, to reduce their weight and the pain in their knees. While this might not be on a 'menu of options', it illustrates the importance of treating a menu like this only as an indication of what's available, not a comprehensive list.'

Heather Burbidge, Specialist Rheumatology Nurse, Portsmouth Hospitals NHS Trust

'I think clinical consultation times will need to be extended for patients with personal health budgets, because the standard 15-minute appointment is not sufficient to enable people to properly discuss the risk assessment and decision making they need when forming a care plan.

I also feel that nurses will find their role as patients' advocates more challenging under a personal health budgets system, because in advising on which services to include they will need to balance their clinical knowledge with patients preferences – and these may not always match. In such circumstances, it is nurses' duty to ensure that patients' decisions are properly informed.'

APPENDIX IV: PARTICIPANTS

Arthritis Research UK is grateful the following participants in our one-day workshop and seminar, as well as anyone that we have inadvertently omitted from this list:

One-day workshop participants:

Philip Ainsworth, British Society of Rheumatology
Alison Austin, Department of Health
Lexy Barber, Arthritis Care
Cathy Barnfield
Deloreen Bartley, Department of Health
John Bates
Colin Beever, Portsmouth Hospital NHS Trust
Sue Bennett
Ailsa Bosworth, National Rheumatoid Arthritis Society
Rita Brewis, In Control
Vicky Chamberlain, Royal College of Nursing
Amanda Cheesley, Royal College of Nursing
Debbie Cook, National Ankylosing Spondylitis Society
Charles Dobson, Department of Health
Jane Dunnage, Lupus UK
Ron Finlay, Ron Finlay Communications
Eleanor Goddard
Laura Guest, British Society of Rheumatology
Michael Haslam, Department of Health
Ray Heal, Dorset Personal Health Budget Pilot
Jamie Hewitt, National Rheumatoid Arthritis Society
Anne House
Nikki Joule, Diabetes UK
Gail Johnston, Havering Pilot Site
Phillipa Jose, Arthritis Research UK
Claire Kilby
Mike Kimmons, The British Orthopaedic Association
Nora Kirkwood
Terry Lawrence
Tracey Loftis, Arthritis Research UK
Suzanne Magem, College of Occupational Therapists
Jacqui Manning, Arthritis Research UK
Louise May
Rowena McCarthy
Ros Meek, ARMA
Vicki Minchin, Arthritis Research UK
Gemma Newbery, Nottingham City Pilot Site
Sally Ore, Department of Health
Liam O'Toole, Arthritis Research UK
Catherine Percy, Primary Care Rheumatology Society
Trudy Reynolds, Oxfordshire Pilot Site
Valerie Richardson
Kate Ring
Tori Salmon, Chartered Society of Physiotherapy
Steve Sharples
Debi Simpson
Sue Sloane
Pam Stewart, Fibromyalgia Association
Lynne Stockbridge, Chartered Society of Physiotherapy
Kirsty Walker, Arthritis Research UK

Gina Walton, Eastern and Coastal Kent Personal Health Budget Pilot
Anne Wilby

Policy seminar participants:

Vidhya Alakeson, Resolution Foundation
Ian Bernstein, Gordon House Surgery General Practice
Neil Betteridge, Neil Betteridge Associates
Laura Boothman, Arthritis Research UK
Rita Brewis, In Control
Judith Brodie, Arthritis Care
Heather Burbidge, Portsmouth Hospital NHS Trust
Jo Cumming, Arthritis Care
Benjamin Ellis, Arthritis Research UK
Peter Elms, PLMR
Yvonne Fagg, Teeside Personal Health Budget Pilot
Ron Finlay, Ron Finlay Communications
Kirsty Freeman, Teeside Personal Health Budget Pilot
Eleanor Goddard
Inam Haq, Arthritis Research UK
Jamie Hewitt, National Rheumatoid Arthritis Society
Isabel Hodgkinson, Royal College of General Practitioners
Phillipa Jose, Arthritis Research UK
Tracey Loftis, Arthritis Research UK
Richard Malham, The Academy of Medical Sciences
Rowena McCarthy
Gopa Mitra, Proprietary Association of Great Britain
Federico Moscigui, Arthritis and Musculoskeletal Alliance
Liam O'Toole, Arthritis Research UK
Catherine Percy, Primary Care Rheumatology Society
Nick Phal, British Acupuncture Council
Madeline Randall, National Ankylosing Spondylitis Society
Kate Ring
Sue Roberts, Year of Care Partnerships
Steve Sharples
Alan Silman, Arthritis Research UK
Caroline Skevington, Nottingham Personal Health Budget
Di Skingle, People with Arthritis/Rheumatism in Europe
Debbie Smith, British Society for Rheumatology
Pam Stewart, Fibromyalgia Association UK
Dawn Stobbs, Department of Health
Veronica Thiel, Freelance Researcher
Beth Thompson, Wellcome Trust
Peter Wasson, The Patients Association

REFERENCES

1. Department of Health (July 2010). Early experiences of implementing personal health budgets, PSSRU Discussion Paper.
2. Department of Health (November 2010). Experiences of implementing personal health budgets: 2nd interim report.
3. Department of Health (July 2011). The cost of implementing personal health budgets, PSSRU Discussion Paper.
4. Department of Health (October 2011). Personal health budgets: early experiences of budget holders. Fourth Interim Report, Personal Health Budgets Evaluation.
5. Department of Health (June 2012). Personal Health Budgets: Experiences and outcomes for budget holders at nine months. Fifth Interim Report Personal Health Budgets Evaluation.
6. Department of Health (October 2011). Personal health budgets: early experiences of budget holders. Fourth Interim Report, Personal Health Budgets Evaluation.
7. Alakeson V. (January 2011). Active patient: the case for self-direction in healthcare.
8. NHS Future Forum (June 2011). Choice and Competition: Delivering Real Choice.
9. Department to Health (June 2011). Government response to the NHS Future Forum.
10. Royal College of General Practitioners Clinical Innovation and Research Centre (2011). Care Planning: Improving the lives of people with long term conditions.
11. Right Care (November 2011). The NHS Atlas of Variation in Healthcare. Reducing unwarranted variation to increase value and improve quality.
12. Department of Health (December 2011). England level programme budgeting data 2010-11.
13. Arthritis Research UK National Primary Care Centre, Keele University (October 2009). Musculoskeletal Matters.
14. Wiles N et al. (1999). Estimating the incidence of rheumatoid arthritis – Trying to hit a moving target? *Arthritis & Rheumatism* 42(7),1339–46.
15. Breedveld F. (2004). Osteoarthritis – the impact of a serious disease. *Rheumatology* 43 (Suppl 1)i4-i8.
16. National Institute for Health and Clinical Excellence (February 2008). NICE Clinical Guideline: The care and management of osteoarthritis in adults.
17. Arthritis Care (May 2012). OA Nation.
18. Department of Health (October 2011). Personal health budgets: early experiences of budget holders. Fourth Interim Report, Personal Health Budgets Evaluation.
19. Department of Health (October 2011). Personal health budgets: early experiences of budget holders. Fourth Interim Report, Personal Health Budgets Evaluation.
20. Arthritis Research UK (2009). Complementary and alternative medicines for the treatment of rheumatoid arthritis, osteoarthritis and fibromyalgia.
21. Department of Health (October 2011). Personal health budgets: early experiences of budget holders. Fourth Interim Report, Personal Health Budgets Evaluation.
22. Alakeson V. et al. (January 2011). Active patient: the case for self-direction in healthcare.
23. The Health Foundation (September 2010). Personal health budgets: research scan.
24. The Health Foundation (July 2011). The Dutch experience of personal health budgets.
25. Audit Commission (October 2010). Financial Management of personal budgets, challenges and opportunities for councils.

ACKNOWLEDGEMENTS

Arthritis Research UK is very grateful to all those who have contributed to this report, particularly the survey respondents, one-day workshop and seminar participants.

In producing this report Arthritis Research UK has considered the contributions of individuals (see Appendix IV), but the report should not be taken as representing the views either of individual participants or their organisations.

We thank ICM Direct for processing, coding and analysing the survey questionnaires.

Arthritis Research UK

Arthritis Research UK is the UK's fourth largest medical research charity. Our vision is 'a future free from arthritis'. Our remit includes arthritis and musculoskeletal conditions, which are disorders of the joints, bones and muscles – including back pain – along with rarer systemic autoimmune diseases such as lupus. Together, these conditions affect around ten million people across the UK and account for the fourth largest NHS programme budget spend of £5 billion in England.

Arthritis is the biggest cause of pain and disability in the UK and with other musculoskeletal conditions accounts for 20% of patients consulting with their GP. As a charity we fund research, provide information to patients and educational resources for health professionals.

Registered charity in England and Wales No. 2077711, Scotland No. SCO41156

A Company registered in England and Wales and Limited by Guarantee No. 490500

Arthritis Research UK
Copeman House, St Mary's Gate
Chesterfield, S41 7TD

www.arthritisresearchuk.org