

West Berkshire Neurological Alliance

Representing people in Berkshire West affected by a neurological condition

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Pain services in NHS Berkshire West. Recommendations to commissioners November 2009

Recommendations.

1. It is recommended to retain the existing pain services in Secondary and Tertiary Care and to promote awareness of their existence and capabilities.
2. It is recommended that the Tertiary Care pain services at Oxford and Southampton carry out a joint review, aiming for them to ensure that where possible all services are available at both centres of excellence.
3. It is recommended that Primary Care pain services are upgraded and made more consistent through establishment of a common care pathway for patients affected by pain. This could be instigated by the appointment of one practicing clinician within NHS Berkshire West to be clinical lead for pain services and clinical champion for relief from pain.
4. It is recommended that the appointment made is of a GpwSI(Pain) who works part time as a conventional GP but in addition who devotes a significant amount of time (indicated at 23 x 3 hour sessions pa, plus associated training and supervision) to provide specialist pain consultations and to ensure that a common pathway and set of procedures for the best management of pain is introduced and that GP and other clinician colleagues have up-to-date information about pain and options for best management,
5. It is recommended that the pain care pathway should include those patients experiencing pain normally should complete a standardised 'Pain Inventory' and keep a 'Pain Diary', being central to achieving commonality of process and a consistent approach to assessment of needs and associated decision-making.
6. It is recommended that the GpwSI(Pain) establishes a Primary Care Pain Clinic and that, when in session, this operates as a multidisciplinary unit with the doctor supported by nurse, physiotherapist, psychologist and Occupational Therapist staff in attendance, as outlined in 'A practical guide to the provision of Chronic Pain Services for Adults in Primary Care'.
7. It is recommended that the GpwSI(Pain) acts as the main link on the subject of pain between Primary Care and the Secondary and Tertiary Care pain services.
8. It is recommended that the (developing) advice in the Draft Essence of Care Benchmark for Pain Management be adopted, for purposes of establishing, maintaining and improving quality of the pain service.
9. It is recommended to set aside a budget of £18,000 for one year to set up this service and evaluate its impact. West Berkshire Neurological Alliance will consider grant aiding these proposals up to a maximum of £4,500, subject to further discussion about detailed arrangements. The possibility of co-funding with the South Central Innovation Fund or the Berkshire West Partnership Development Fund should be considered.
10. Consideration should be made to conduct a one-day pain prevalence survey at one GP practice of all attending patients, as recommended in 'A practical guide to the provision of Chronic Pain Services for Adults in Primary Care'.
(Reproduced in Appendix 3.)

11. The potential benefits of appointing additional GpwSI(Pain), GPwSI(Headache) or Migraine Nurse Specialist should be investigated in tandem with the above.

Basis of the recommendations:

Existing Secondary and Tertiary Pain services are broadly fit for purpose, although not equitably available, accessible or accessed. Some internal rebalancing would appear to be needed. The services need to raise awareness of their existence and capabilities, to clinicians and to the general public.

Existing Primary Care pain services are not consistently provided, despite pain being the third most common reason why patients visit their GPs. The cost of poorly treated pain is significant, in both clinical and financial terms and improving consistency and quality should benefit many patients.

In Primary Care there is an over-dependency on pharmaceutical intervention for pain management and insufficient awareness of and referral to non-pharmaceutical treatments and therapy options.

Pain management should, wherever possible, be the responsibility of the patient whose main information, advice and support should, in most instances, come from within Primary Care.

The following have been taken into account in arriving at these recommendations.

1. Summary of the proceedings of a CPD accredited pain conference held at the Arlington Arts Centre near Newbury on 9th July 2009. (Extracts in Appendix 1)
2. Findings of a survey into people's experiences of living with pain, conducted during July-September 2009 by West Berkshire Neurological Alliance (on the Internet) for service users within the NHS Berkshire West catchment. (Appendix 2)
3. 'A practical guide to the provision of Chronic Pain Services for Adults in Primary Care', published by The British Pain Society and the Royal College of General Practitioners. (October 2004). (Extracts in Appendix 3)
4. Department of Health 'Essence of Care; Consultation on the new benchmarks for pain' (July 2009 ongoing). (Extracts in Appendix 4)
5. A new GP with special interest headache service: observational study. Ridsdale L, Doherty J, McCrone P, Seed P, Headache Innovation and Evaluation Group. British Journal of General Practice, March 2008. (Extracts in Appendix 5)

Clinical and financial implications.

The general cost of pain is substantial. Extrapolation of the national data in Appendix 3:

- There are approximately 700,000 people in NHS Berkshire West suffering chronic pain
- Over 4,000 people in NHS Berkshire West suffer neuropathic pain
- Poorly managed chronic pain accounts for about 1.73 million days off work in NHS Berkshire West equating to about £150 million a year lost earnings.

Extrapolation from the data in Appendix 5, the cost of a GpwSI(Headache) clinic, providing a service to 150 patients pa, giving good clinical outputs and good patient satisfaction, based on 23 x 3 hour sessions pa, with associated training, supervision and administration support was approximately £16,735 at 2007/8 prices. This is in the range 56-67% the cost of providing the same quality of service in secondary care. Allowing

for annual inflation, the budget in the preceding paragraph indicates a need for £18k for purposes of preliminary budgeting for 2010/11 for one GP specialist. There is no published research data on the savings to be made within the NHS of managing pain better. Noting that all the initial consultations will happen anyway, because the patients are in pain, it is projected that savings should be achievable under the following headings:

- a higher rate of successful consultations will reduce the number of follow-up consultations, saving 'conventional' GP time
- reduction in inappropriate pharmacy
- reduction in total pharmacy
- substitution of NHS-cost pharmacy by non-NHS-cost, non-pharmacy interventions

The above may be offset by new, higher NHS costs:

- increased referral to secondary/tertiary care
- increased referral to physiotherapy and Talking Therapies services, noting that these services are currently under rapid expansion and able to take new capacity

The above headings should be the basis of cost monitoring. In addition there should be clinical outcomes and patient satisfaction monitoring.

Appendix 1

Summary of the proceedings of a CPD accredited pain conference held at the Arlington Arts Centre near Newbury on 9th July 2009.

The conference was CPD accredited and the speakers included two NHS Consultant Professors, six doctors a patient representative and practical sessions of non-pharmacological options for managing pain. Of the 120 delegates, 70 were practising clinicians and in the exit survey delegates reported high levels of relevance towards understanding and improving pain management options and practice.

Definition of pain

‘Pain is whatever the person experiencing it says it is and it exists whenever the person communicates or demonstrates it does’ (adapted from McCaffrey M 1968) and ‘an unpleasant sensory and emotional experience associated with potential tissue damage or described in terms of such damage’, (Merskey and Bodguk 1994). Every person will experience acute pain and at any given time about one in seven experience chronic or long-term pain.

Main types of pain

Pain has many guises, sometimes without obvious pathology.

Acute pain is caused by damage to the body, involving relatively well-researched chemical processes linked to transmission of messages, followed usually by healing and adaptation. Rubbing pain away is an example of a distraction process that often works. Post-operative and some other acute pains generally respond to morphine, so treatment of cancer and some other pains have much improved since earlier times.

Chronic pain is a continual process that can be described within a bio-psycho-social model. Such pain usually has little or no obvious pathology. Psychological, emotional and cognition factors may all come into play and chronic pain may not be static

Fibromyalgia pain is processed in a different way to those with other forms of pain, affecting how fibromyalgia pain might best be managed.

Neuropathic pain affects some 500,000 individuals in the UK. About 1 in 4 with diabetes will develop such pain and about 1 person in 4 attending a specialist pain clinic will have neuropathic pain. Treatments that reduce of the activity of neuro receptors known as NMDA receptors can be helpful. Tricyclic antidepressants, used at about one fifth the anti-depressant use level can be effective. Also, Gabapentin can be effective and cannabinoids have been shown to reduce the perception of neuropathic pain. Opioids are ineffective for neuropathic pain.

Stroke, traumatic and demyelinating-inflammatory pain. There are different physical differences that arise between stroke, traumatic and demyelinating-inflammatory (e.g. MS) injury. Specific damage can lead to specific loss of muscle movement and these muscles may need support or specific exercise or therapy. Each patient requires individual diagnosis, understanding and a choice of treatment options.

70% of those with central post-stroke pain respond to pain relieving drugs. Early treatment following traumatic brain injury is very important, recognising that over-sedation can slow down rehabilitation.

Spasticity pain. There is a high correlation and interaction between spasticity and pain, emphasising the importance of keeping muscles moving as much as possible.

Spinal cord pain. Spinal cord pain is unique, being similar to acute pain but perhaps lasting for many years. 65-85% of spinal cord injury patients report pain, of which about 1 in 3 report severe pain. This can affect sleep, tasks of daily living, work, quality of life, depression and family relationships. Life in general can be difficult to manage. Recent data indicates that no specialist centres currently provide all the care that meets these standards. Changes needed include better information, better education of clinicians, shared understanding, evidence based prescribing, better admissions procedures, better educating of the patients about pain management options, better needs assessments, better goal setting better documentation and more holistic plans.

Parkinson's pain. Pain is reported by some 65-85% of individuals with Parkinson's Disease, compared to only two thirds such patients who experience tremor. In a typical 15-year decline a Parkinson's patient will probably experience musculo-skeletal pain, dystonic pain and variants of neuropathic pain. Delayed diagnosis of Parkinson's can delay management and therefore delay pain relief. In particular this can affect lumbar radicular pain, osteoporotic collapse, epidural abscesses and cervical pain. Dystonic pain can lead to inversion of the feet. Central neuropathic pain is associated with lesion or dysfunction of the thalamus and problems with the sensory circuits of the basal ganglia. Parkinson's patients often describe stabbing or burning pain. Some report crawling, burning or tingling pain and this responds to dopamine treatment but can also be caused by it.

Treatment options

Exercise and mobility are very important in pain relief. Immobility often makes pain worse.

Warm water hydrotherapy can be effective in pain relief.

Cognitive Behavioural Therapy and other talking therapies can work well for pain relief. Assessing cognitive, emotional, interpretational and coping ability should lead to an outcome appraisal. Psychological counselling is generally aimed at converting 'threats' into 'pain relief'. Positive thinking and positive activities are key success factors. Results might take up to three months to show. The psychological therapist should work with the patient, understand them in context, should listen and be aware that the situation continues to evolve, should conduct therapy in a relaxed environment and set realistic goals, appraising outcomes as therapy proceeds.

Some alternative therapies may work equally well, such as Hypnotherapy, Myofascial release, Acupuncture, TENS, reflexology, massage, aromatherapy and Tai Chi, among others.

Destruction of nerves is effective, but rarely a good option.

Pharmacy and polypharmacy also may have a role in pain relief. Paracetamol, copramol, weak opioids, tramadol, NSAIDS, COX2 Inhibitors, tricyclic antidepressants, codeine, gabapentin, cannabinoids and others each target pain in different ways. Pain

pharmacy can be taken orally, or by injections, implants, or spinal cord stimulators. Too illustrate in just one sector, Gabapentin, amitriptyline, tramadol, oxycodone and carbamazepine as having potential in treating some spinal cord injury pain.

In summary, controlled exercise, linked to rational poly-pharmacy, linked to sensible use of every other relevant option will bring greatest levels of pain relief. 'No more pain' is probably not realistic, but 'less pain' is realistic. Patients who take responsibility and work with pain experts can expect to suffer less and generally lead a fairly normal life. The place to start is to seek expert advice and take a positive approach throughout.

The importance of best management

Chronic or long-term pain affects one person in seven and is a major cause of lost days of work and poor quality of life.

Pain can affect sleep, cause fatigue, lead to secondary illness and feelings of uselessness, anxiety, depression and reduced mobility. A poor environment such as the lift to the home not working, low wages, no car, poor access to shops or poor diet, can have a cumulative effect. Spiritual confidence can take a knock or become lost.

Prompt and accurate diagnosis of chronic pain is often neglected, leading in some instances to people suffering pain much longer than they should, increasing the cost.

A new option for better management: GP with Special Interest in Pain

Pain has not been allocated a Quality and Outcomes Framework (QOF), meaning that GPs are not rewarded specifically for treating patients affected by pain. GP training does not embrace management of chronic pain. Acute pain is generally well managed by prescription but chronic pain is often poorly investigated and poorly managed.

To manage chronic pain better requires a more skilled approach at GP level. There are very few GPs with Special Interest in the country and where they exist they make a significant impact on quality of life for patients in pain.

In reality, the 10-minute appointment the patient has with the GP is only 8 minutes and therefore patients must prepare well before their consultation. GpSwSI in Pain recommend that patients with pain should be encouraged to complete a brief pain inventory and keep a pain diary for two weeks.

A holistic assessment by the GP or GpSwSI should involve study of the inventory and diary, followed by listening to what patients say (and do not say), followed by a physical examination. The purpose is to empower the patient and to set realistic goals. Reduction of pain scores 'from nine to zero' may generally not be realistic, but 'nine reduced to three' may well be realistic, leading to the patient enjoying a functional life.

It is recommended to employ a GPwSI in Pain and use the 'Pain Toolkit' and follow NICE guidelines. Thorough and expert assessment, covers psychological, emotional, family and work issues. Management involving paced exercise is usually important. Typical goals might include reducing dependency on aids, alcohol and drugs. Overly protective family and friends who may take over tasks of daily living should be discouraged. Factors such as job satisfaction are known to reduce pain. A multi-disciplinary plan to manage pain is likely to achieve the optimum results.

Appendix 2

Findings of a survey into people's experiences of living with pain

WBNA Pain Management Survey

Background

The West Berkshire Neurological Alliance (WBNA) currently represents 25 organisations, representing over 30 conditions

In July 2009, the West Berkshire Neurological Alliance (WBNA) organised a one-day conference, *Brains, Pains & Gains*, on pain and pain management.

Whilst organising this event, it was decided that it would be good to get some information on patients' experiences of pain and pain management in the West Berkshire area.

In the spring of 2009, the WBNA therefore carried out a Pain Management Survey of people living with pain who are living or working in the Berkshire West NHS area of Reading, Wokingham & West Berkshire.

Survey Overview

The survey consisted on 8 questions, many with multiple answers. Survey respondents were also asked and encouraged to make comments as part of the survey, in order to better illustrate the bare results.

The survey was uploaded to the online survey management system provided by SurveyMonkey.com.

The survey was publicised through the WBNA member organisations and through local publicity, such as distribution of information cards to local pharmacies.

Survey Results

Sixty-seven people started the survey and, of these, only 57 completed the full survey. In order to ensure that survey respondents fulfilled the required criteria, they were first asked to confirm that they were living or working in the Berkshire West NHS area of Reading, Wokingham & West Berkshire and that they experienced either acute or chronic pain. If they did not answer yes to both these questions, survey respondents were unable to continue with the survey.

Acute pain was described as temporary pain that is expected to resolve, e.g. pain from a recent injury. Chronic pain was described as lasting 3 months or more whether intermittent or not or whether including flares of acute pain or not. Ninety-five percent (n=64) of survey respondents suffered from chronic pain, with 7.5% (n=5) suffering from acute pain.

Survey respondents suffered from a number of chronic conditions causing pain, including:

Arachnoiditis

Arthritis

Cerebral Palsy

Diabetic Peripheral Neuropathy

Fibromyalgia Syndrome

ME/CFS

Multiple Sclerosis

Myofascial Pain
Polymyalgia Rheumatica
Post Polio Syndrome
RSI
Sciatica
Scoliosis
Sickle Cell Disease

Spinal fusion
Spinal Injury
Stroke
Transverse Myelitis
Trigeminal Neuralgia
Vulvodynia

The most prevalent conditions suffered by survey respondents were arthritis (20%, n=13) and Fibromyalgia Syndrome (33%, n=21). Eleven percent (n=7) of survey respondents said that they were undiagnosed.

Survey respondents were asked “To what extent has pain impacted on your life in the last month?” with the options of “Great Impact”, “Moderate Impact”, “Little Impact”, “No Impact” and “Don’t Know”. Sixty percent of respondents (n=38) said that pain had had a great impact on their life in the last month, with 37% (n=23) saying moderate impact and 3% (n=2) saying little impact.

Forty-seven survey respondents commented on this question, with remarks such as:

“Pain and weakness is draining and prevents me from doing what I would otherwise do.”

“My pain has affected the quality of my life and my relationships.”

“Previously an extremely active person with a busy social life, now as my husband says I have become a withdrawn individual frightened to be away from the comfort of my home”

“It limits how much I can do, how far I can walk and interferes with my sleep”

“Although pain has had only a moderate impact on my life in the last month, in the last few years pain has, at times, had a severe impact on my life”

“I cannot walk far or stand for long, this causes weight gain and causes more recurrent pain and tiredness.”

Survey respondents were then asked “How satisfied are you with how your pain is managed?” with options of “Very satisfied”, “Satisfied”, “Moderately satisfied”, “Slightly satisfied”, “Not satisfied at all” and “Don’t know”. Twenty-seven percent (n=17) of respondents were not satisfied at all with how their pain was managed, 37% (n=23) were slightly satisfied, 18% (n=11) were moderately satisfied, 11% (n=7) were satisfied and only 3% (n=2) were very satisfied with how their pain was managed.

Forty-one survey respondents commented on this question, with remarks such as:

“Being on a cocktail of prescribed and over the counter medications barely manages the pain”

“After 14 months of chronic pain a new GP has referred me for pain management”

“Progress is extremely slow, with no real diagnosis.”

“No medication appears to get rid of the pain. It only eases it very slightly.”

“My GP is very good and helps a lot but access to pain management is too limited.”

“Pain is brushed under the carpet while other things are looked at because to the doctor they are more important as they are easier to deal with”

“Have had to search for information and treatment myself”

“My pain could be better managed through higher doses of medications and more lifestyle adjustments, but at the moment, neither of these is possible and I have to suffer as a result - alternatives are not easy to access”

Survey respondents were then asked: “Have any of these people helped you to control or manage your pain and if so, how much have these people helped you?”. The question then gave a list of healthcare professionals, from NHS Pain Consultants to Private Osteopaths, and the options of “No help”, “A little bit of help”, “A reasonable amount of help”, “A lot of help” and “N/a or don’t know”.

If we look at the results for each category of healthcare professional, excluding those that responded “N/a or don’t know”, the results are as below.

Type of healthcare professional	No help	A little bit of help	A reasonable amount of help	A lot of help
NHS Pain Consultant (n=24)	33% (n=8)	42% (n=10)	13% (n=3)	13% (n=3)
NHS Neurologist (n=17)	65% (n=11)	29% (n=5)	0%	6% (n=1)
NHS Neurosurgeon (n=9)	56% (n=5)	11% (n=1)	11% (n=1)	22% (n=2)
NHS Rheumatologist (n=13)	46% (n=6)	23% (n=3)	23% (n=3)	8% (n=1)
Other NHS consultant (n=14)	36% (n=5)	43% (n=6)	7% (n=1)	14% (n=2)
NHS GP (n=47)	11% (n=5)	45% (n=21)	21% (n=10)	23% (n=11)
NHS Pain Nurse (n=6)	50% (n=3)	0%	33% (n=2)	17% (n=1)
NHS Physiotherapist (n=17)	53% (n=9)	29% (n=5)	12% (n=2)	6% (n=1)
Pharmacist (n=11)	45% (n=5)	18% (n=2)	18% (n=2)	18% (n=2)
Private Consultant (n=13)	31% (n=4)	31% (n=4)	8% (n=1)	31% (n=4)
Private Physiotherapist (n=16)	31% (n=5)	25% (n=4)	13% (n=2)	31% (n=5)
Private Chiropractor (n=12)	42% (n=5)	33% (n=4)	25% (n=3)	0%
Private Osteopath (n=16)	19% (n=3)	31% (n=5)	31% (n=5)	19% (n=3)
Private massage therapist (n=15)	20% (n=3)	33% (n=5)	20% (n=3)	27% (n=4)

Healthcare professionals and therapies mentioned by survey respondents in the comments that were not otherwise listed included: hypnotherapy; acupuncture; speech therapy; yoga; exercise; Chinese herbal medicine; Palliative care consultant;

McTimoney chiropractic; reflexology; shoulder consultant; private CBT (Cognitive Behavioural Therapy) from a psychologist; Trauma & Orthopaedics consultant; MS Occupational therapist; Trigeminal Neuralgia Nurse; and Post Polio Consultant at St Thomas' Hospital.

Other comments on this question by survey respondents included:

“Pain consultant was sympathetic but said he didn't know how to help.”

“As my pain condition is an enigma, sadly in the 21st century nobody in the medical or healthcare profession has been able to diagnose the cause”

“I paid for acupuncture was good but could not continue as the cost was becoming too much.”

“I have seen different people, but unfortunately they are only interested in their own speciality and are not prepared to listen when it comes to the whole problem of pain. They tell you that you are there because of your back, or knee, or face: they are not interested in the whole body.”

“I have never been referred to any of the above.”

“I also have reflexology & this helps a lot, but I can only have this for 4 months of the year, due to cost as I go to a local training college. It starts in February, ends in June. By October I am in so much pain I cannot function properly”

“My NHS GP is brilliant, but actually, all the suggestions and specialist therapies that keep my pain under control have come from private practitioners - my NHS GP helps by issuing the prescriptions that my private consultant suggests”

The survey respondents were then asked “Overall, have you experienced prompt and effective help from the NHS with managing your pain?”. Only 14% (n=8) of the survey respondents replied “Yes” and 74% (n=43) replied “No”.

Comments from survey respondents on this question included:

“I had a very good GP who was really helping through it, but she has left. Don't feel quite so supported with new GP.”

“Still very slow progress after 15 months.”

“I've just been told that "there is not much we can do about it".”

“I have had to rely on my company's medical insurance and funding physiotherapy myself.”

“Because of the undiagnosed cause of the severe pain I am suffering it would be a fair comment for me to say the NHS has been of little help”

“All the NHS did was offer me amitriptylene which after 5.5 years made me into a zombie. My family thought I had a form of dementia until I stopped taking it and very slowly recovered”

“Advice from the Pain Clinic was basically 'get used to it'. My GP is prompt at dishing out the drugs but they don't work, and every time I'm referred to a specialist it seems to take forever waiting for an appointment”

“Under NHS care, my pain was severe, debilitating and very poorly managed. I had to go private to get the help I needed to enable me to live my life.”

Survey respondents were then asked: “Of these services, how many are you aware of and how many have been referred to?”, with the question then giving a list of services that are specifically used for pain management and the options of “Referred and found useful”, “Referred but didn't find useful”, “Aware of but haven't been able to access”, “Aware of but have not wanted to access”, “Not previously aware of” and “Don't know”. Excluding those responses of “Don't know”, the results were as follows:

	Referred and found useful	Referred but didn't find useful	Aware of but haven't been able to access	Aware of but have not wanted to access	Not previously aware of
NHS Pain Clinic locally (n=43)	19% (n=8)	16% (n=7)	16% (n=7)	9% (n=4)	40% (n=17)
NHS Pain Service out of local area (n=41)	10% (n=4)	5% (n=2)	10% (n=4)	5% (n=2)	71% (n=29)
NHS Physiotherapy (n=44)	25% (n=11)	27% (n=12)	20% (n=9)	23% (n=10)	5% (n=2)
Complementary therapies on the NHS, e.g. acupuncture, TENS machines (n=46)	9% (n=4)	26% (n=12)	26% (n=12)	15% (n=7)	24% (n=11)
NHS Counselling (n=42)	10% (n=4)	7% (n=3)	19% (n=8)	19% (n=8)	45% (n=19)
NHS Cognitive Behavioural Therapy (CBT) (n=39)	0%	18% (n=7)	23% (n=9)	21% (n=8)	38% (n=15)
Hydrotherapy (n=42)	10% (n=4)	2% (n=1)	24% (n=10)	12% (n=5)	52% (n=22)
Exercise schemes for people with chronic health conditions (n=41)	2% (n=1)	10% (n=4)	20% (n=8)	5% (n=2)	63% (n=26)
Expert Patient Program (also known as the Living Well course) (n=41)	20% (n=8)	10% (n=4)	5% (n=2)	20% (n=8)	46% (n=19)
Prescription medications for pain relief (n=50)	64% (n=32)	22% (n=11)	8% (n=4)	6% (n=3)	0%
Over the counter medications for pain relief (n=34)	44% (n=15)	41% (n=14)	3% (n=1)	6% (n=2)	6% (n=2)

Comments from survey respondents on this question included:

“There are a number of things that I know would help me better manage my pain - such as hydrotherapy and specialised exercise programs - that I haven't been able to access at all.”

“I have paid privately for acupuncture, physiotherapy, and two sessions of CBT. All these were very expensive and now because for me a hydrotherapy pool is beneficial I pay £65 a month to go somewhere in Wokingham which takes me nearly an hour to get there. This is all very expensive when you are on a pension. I find it more difficult to access things as although I live in West Berks my surgery is in South Oxon.”

“I am now appalled to find how many other options I could have had. I spent over £1000 on private acupuncture treatment unaware that it might be available on NHS. This has really [annoyed me] to know that I could have been getting more help”

As the above table of results shows, none of the survey respondents who had been referred to CBT or Cognitive Behavioural Therapy on the NHS had found this service useful. One quote from a respondent on this subject was:

“Referred for Blues Begone programme. Found this to be ineffective due to inadequate nature of DVD. Felt like I was being fobbed off by GP and organising staff, as if the process of giving me the DVD was to their mind a tick in a box rather than an effective treatment.”

The survey respondents were also encouraged to comment at the end of the survey and these comments included:

“I haven't driven a car, or sat down properly since January (it is now May) - I have stood up to use my laptop, to eat any food, to do any writing. The pain has been so bad at times that I have considered suicide. Now, several months down the line, I happen to pick up a card in my pharmacy and do this questionnaire only to discover that something could have been done much sooner to deal with it. I have ended up on anti-depressants and fear I will lose my job because I can't manage the pain. WHY is all this kept secret? WHY don't you tell people about what is available? I'm a very self-directed patient but I have somehow completely missed the majority of treatments on offer. How can this happen?”

“It feels as though it has been a battle from the start. There seems to be very little specialist knowledge around. Doctors seem to think the pain is a minor side effect rather than the real problem that stops me doing the things I really want to do.”

“I have been told that there isn't much that can be done. I'm aware that there are other drugs/treatments available, but I haven't been offered anything. Perhaps I've made too little of my discomfort, as I do try to carry on as normal, and if I

pressed more I might get further, but my overall impression is that GPs are not all that knowledgeable about Fibromyalgia and how to deal with it.”

“All I can ask is when a person presents with multiple problems the doctors do not just give up and say “sorry I cannot help you because there is too much damage” or say “you are here because you need a left knee replacement, so that is all I can talk about right now. If the right knee is hurting or your back is hurting then make another appointment“. That really does get me annoyed”

“We need faster access to pain clinics. We need the ongoing use of hydrotherapy pools . This is very difficult as there are so few available and I don't see this changing as the NHS cannot cope with demand at the moment. We need quicker access to physiotherapists before conditions which are acute become chronic.”

Conclusion

The survey results have highlighted the fact that chronic pain affects people with a wide range of different diagnoses. Although the conditions are different, the experiences and needs of patients are often similar.

Awareness of options for pain management, the accessibility of those options, and their effectiveness varies widely. Some survey respondents were quite upset by the number of options available that they had not been made aware of.

Almost all of the respondents were aware that prescription medications for pain relief, over the counter medication for pain relief and NHS physiotherapy are options. But awareness of other services varies considerably, with less than a third of respondents being aware that there are exercise schemes for people with chronic health conditions and that there are specialist NHS Pain Services out of area. So being a patient in pain does not mean that you are made aware of all the services that may be helpful in managing your pain. Researching options is something that many patients have to do for themselves, but this is not easy, particularly if you are new to needing healthcare or are in a lot of pain. Some of the respondents were actually quite upset to find out that there are so many options that they didn't know about. Further work is needed in making it easier for patients to find out about all the pain management options that are available.

The survey results showed that even if patients are aware of services that may help with pain management, they may not be able to access them if they want to. The struggle to access services was something that many survey respondents commented on, saying that they did not have the energy to always be chasing up other options.

The survey results also highlighted the fact that the more easily accessible treatments are not always the most effective, especially as perceived by the patients in the context of quality of life, rather than just pain levels.

All survey respondents were aware that Prescription medication for pain relief was an available option and most respondents who wanted to could also access it. Of those who did access this option, a majority also found it useful. Most survey respondents were aware that Over the Counter medications for pain relief were an option and were able to access this option if they wanted. However, only 52% of those that did access this option found it useful. Many respondents also commented that medications could not

control pain effectively on their own, or that higher doses of medications could provide greater pain control but often at the expense of quality of life.

The survey results showed that NHS Physiotherapy and Complementary Therapies on the NHS have low levels of usefulness compared to relatively good levels of awareness and accessibility. Hydrotherapy on the other hand has relatively poor levels of awareness and accessibility, but 80% of the respondents who managed to access Hydrotherapy found it useful. And exercise schemes for people with chronic health conditions had relatively low levels of awareness, accessibility and usefulness amongst respondents.

The importance of focusing on the patient's quality of life was highlighted by a survey. Patients want to have options and to feel in control of their pain management. Pain management options that impact negatively on quality of life (e.g. if higher doses of medications means significant adverse effects) are often available but are not welcomed by patients.

Discussion

Problems with the online survey system, almost entirely down to inexperience, contributed to the low numbers of respondents, as there were a few occasions when the survey was found to be offline as it had timed out.

On some questions, the low number of respondents mean that the results were of little value. However, overall themes were identified and some of these were extremely interested. Further research is needed, especially into the cost-effectiveness of options in terms of patients quality of life. If a relatively inexpensive option is considered to be a waste of time by a majority of patients, then it is still a waste of resources despite the low cost.

Appendix 3

A practical guide to the provision of Chronic Pain Services for Adults in Primary Care, published by The British Pain Society and the Royal College of General Practitioners. (October 2004). Selected extracts

1. Statistics and impact

The following are reproduced directly from the above report:

- *1 in 7 (13%) of the UK population suffer from chronic pain.*
- *At least 7 million adults in the UK suffer from painful musculoskeletal conditions*
- *Over 500,000 in the UK suffer from neuropathic pain*
- *1 in 4 with diabetes suffer from chronic pain*
- *Untreated pain can affect quality of life for sufferers and carers resulting in helplessness, isolation, depression and family breakdown*
- *Two thirds of people with chronic pain surveyed across Europe reported inadequate pain control with only 16% saying they had seen a pain specialist*
- *Poorly managed chronic pain accounts for 208 million days off work equating to about £18 billion a year*
- *Currently nearly 4.2% of the working population is on Incapacity Benefit, 24% of which are due to diseases of the musculoskeletal system this equates to a cost of £6.7 billion pa.*

2. Methodology to survey prevalence of chronic pain within a GP Practice.

(Reproduced in full from the report.)

Pre-consultation audit of 100 patients who come to the surgery

Having considered surveys to determine how you, as a practice or an individual, manage patients suffering chronic pain, the next part of this audit is to ask patients about their pain and its management.

You should ask every patient who attends the surgery on a particular day (when all the clinicians are present) to complete a pre-consultation questionnaire while waiting to be seen (a suggestion for this questionnaire is included in Section 3). It does not matter why they are attending or who they intend to see. By asking every patient to complete a questionnaire you will be able to ascertain the prevalence of chronic pain in your practice. It is also worthwhile having a simple poster in your waiting room or on the reception desk explaining why you are doing this audit.

Post-consultation audit of patients in pain

Those patients who have come in to the surgery for a consultation in which pain plays a part in their management should be asked to complete the post-consultation questionnaire before leaving the surgery (a suggestion for this questionnaire is also included in Section 3). If a patient volunteers their name then it is worth marrying up the pre- and post-audit surveys.

Appendix 4

Department of Health 'Essence of Care; Consultation on the new benchmarks for pain' (July 2009 ongoing). Selected extracts and commentary.

The table below is reproduced from the consultation paper from the DOH

<i>Factor</i>	<i>Best practice</i>
<i>1. Access</i>	<i>People experiencing pain, or who are likely to experience pain, and carers receive timely and appropriate management of pain</i>
<i>2. Patient and carer participation</i>	<i>People (where able), carers and staff are active partners in the decisions involving pain management</i>
<i>3. Assessment</i>	<i>People have an ongoing, comprehensive assessment of their pain</i>
<i>4. Care planning, intervention, evaluation, review and prevention</i>	<i>People's individualised care concerning pain is planned, implemented, continuously evaluated and revised in partnership with people, staff and carers</i>
<i>5. Knowledge and Skills</i>	<i>People, carers and staff have the knowledge and skills to understand how best to manage pain</i>
<i>6. Self management</i>	<i>People are enabled to manage their pain when they wish to, and as appropriate</i>
<i>7. Partnership working</i>	<i>People, carers and appropriate agencies work collaboratively to enable people to meet their pain management needs</i>
<i>8. Service evaluation and audit</i>	<i>People, carers and staff have the knowledge and skills to understand how best to manage pain</i>

The consultation paper suggests likely indicators for best practice. Some of the key words and phrases likely to appear in future benchmarking for pain services include:

- availability of up to date information about available pain services,
- appropriate and timely pain management,
- accessible services,
- availability of interventions, resources, equipment, personnel and space to provide care,
- self-referral,
- a single point of access,
- a full range of co-ordinated services,
- information about how to access complementary pain management therapies and services,
- equality of access to services,
- decisions about managing pain should be based on informed choice,
- views and preferences should be sought actively,
- people and carers are involved in evaluation of their pain management,
- appropriate referral as required,
- clinicians are competent to recognise when a person is experiencing pain,
- assess pain including severity using, for example, observational scales,
- accommodate different cognitive levels,
- assessment using an evidence-based tool,

- assessment process recognises people's and carers' expectations of good pain management, clinicians are competent to assess,
- pain is observed regularly along with other vital physiological measurements,
- level of pain relief and function to be achieved has a documented rationale for treatment,
- people hold their own records where appropriate,
- protocols, policies and pathways are evidence-based,
- timely, individualised, correct and evidence-based information is provided
- people and carers are provided with ongoing, individualised evidence-based education
- education and training needs of people and carers are assessed and met,
- staff education includes the complexity and impact of pain on people's and carers' social, physical, spiritual, emotional, psychological and economic situation,
- staffs' attitudes to people in pain and pain management are assessed and education put in place to ensure understanding of people's perspectives,
- commissioners have the knowledge and skills to commission a world class service for people with pain and their carers,
- people are offered the opportunity to manage their pain to a mutually acceptable level,
- self-management plans are developed in partnership with people, carers and staff,
- the organisation identifies and removes barriers to people managing their pain,
- monitoring and assessment takes place for people who are self-administering medicine,
- co-ordinated, continuous, consistent and accessible services exist between health and social
- care organisations working in partnership,
- a key worker co-ordinates continuing management and care joint planning,
- joint documentation is utilised in the management of pain across agency boundaries,
- services that support people with pain and their carers are systematically reviewed,
- complaints and concerns are recorded, monitored, analysed,
- service review should include: availability, timeliness, and continuity of services; appropriateness of services for local health care needs; staff attitudes; etc.,
- review information should be used to improve care,
- a written evaluation of pain services should be provided annually by staff and commissioners.

The draft Benchmark includes many other indicators of relevance.

Commentary on the Essence of Care Benchmark Draft.

The Essence of Care Benchmark for Pain Management is a draft, but contains much in the way of conventional wisdom about best practice. Our local research confirms pain services should be commissioned that are more consistent. It is appropriate to retain the existing specialist services in secondary and tertiary care, while ensuring that Primary Care pain services are better planned, delivered, co-ordinated and with better outcomes.

All GPs should work consistently to one, care pathway, using up-to-date knowledge. It is likely that appointing a GP with special interest in pain (GPwSI(Pain)) would be effective, both to establish a common care pathway and ensure that GP colleagues treat patients to a more consistent standard. The alternative of a Nurse Pain Specialist could be considered.

Appendix 5

‘A new GP with special interest headache service: observational study’. Ridsdale L, Doherty J, McCrone P, Seed P, Headache Innovation and Evaluation Group. British Journal of General Practice, March 2008. (Selected extract)

Costs of service models

The estimated annual costs of running the GPwSI clinic are shown in [Table 2](#). In the year from October 2006, 102 appointments were for new patients and 42 for existing patients. The cost per hour was estimated to be £272. Assuming 30 minutes for a first appointment and 15 minutes for a follow-up, this results in costs of £136 and £68 respectively.

Table 2



Estimated costs of running the headache service for 1 year.

By comparison, the cost of neurology appointments nationally (derived from 2006/2007 NHS reference costs) are £203 (interquartile range £132–239) for first appointments, and £121 (interquartile range £80–140) for follow ups. In 2007/2008, the indicative national tariff for neurology referrals is £177 for first appointments and £100 for follow-up appointments.