

## Development

# Mapping care pathways and estimating the number and cost of musculoskeletal chronic pain patients to inform the development and implementation of a new service

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**Background:** Patients living with chronic pain are typically resource intensive, their care requirements are long term and referral to secondary care is not always expeditious. To provide more appropriate, accessible and cost-effective care, Tower Hamlets Primary Care Trust reviewed the needs of the patients, their current care and the numbers requiring treatment for non-malignant chronic pain, initially starting with musculoskeletal pain. **Method:** We estimated the number of people with chronic pain being treated outside general practice by the NHS in Tower Hamlets. A working group established set criteria to define a chronic pain patient. We surveyed appropriate clinicians to determine the approximate number of patients who fitted our inclusion criteria, the approximate number of follow-up appointments they required and their care pathways. Secondly, we estimated the cost of care for chronic pain patients using NHS national tariff and reference cost data. We also took a convenience sample of chronic pain patients and recorded their history of care. **Findings:** The routes and pathways of care are complex and multiple. We estimate between 4.0% and 5.5% of new patients in rheumatology, orthopaedics, occupational therapy and musculoskeletal physiotherapy and up to 90% in the pain clinic are people living with chronic pain. The cost of this care ranged from £296 for a course of physiotherapy to £1911 for a patient seen in physiotherapy, orthopaedic and the pain clinics. **Conclusion:** There is no facility in current management information services that identifies people being treated for non-specific chronic pain; therefore, estimating both the numbers and costs for treating these people is difficult. National tariff and notional cost data provide estimates only, of an 'average patient'; the real cost of these patients is unknown.

**Key words:** chronic pain; cost; service improvement

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## Introduction

Chronic pain patients are typically resource intensive (Maetzel and Li, 2002), due to multiple specialist referrals, the duration of their condition and/or complex routes of care. Identifying these patients at an earlier stage of their chronic condition might avoid entrenching negative beliefs and behaviours (Airaksinen *et al.*, 2004). The International Association for the Study of Pain (IASP) definition of chronic pain is pain that has lasted beyond the normal healing time, usually about three months (IASP, 1986). This definition may be useful in a research setting to classify chronic pain patients but in a clinical setting it is less practical when analysing patient case histories and patient notes. Typically, a patient with chronic pain is referred through the system into more specialist care when it may often be more expeditious to manage these patients using a multidisciplinary approach in primary care and thus avoid unnecessary tests and procedures in secondary care (Carnes *et al.*, 2007). Managing patients with chronic pain is challenging as they rarely present with one condition, they are more likely to have pain in multiple sites and co-morbid conditions (MacFarlane *et al.*, 2001; Carnes *et al.*, 2007). As a result, treatment may involve pain relief, psychological, sociological and physiological care.

A multidisciplinary approach to the management of chronic musculoskeletal pain is thought to be effective (Flor *et al.*, 1992); however, the costs of providing such care are less well documented and depend on the specialist care and the services available (Health Protection Agency, 2006).

Tower Hamlets Primary Care Trust (PCT) commissioned a feasibility study to explore the possibility and cost of providing a multidisciplinary service for chronic pain patients. Identifying patient flow in both primary and secondary care is problematic but these data are required when planning and designing a new service.

This was a pragmatic study aimed to estimate the numbers and costs of patients with chronic pain utilising NHS resources, other than general practice care, in Tower Hamlets in both primary and secondary care, in order to estimate activity and cost for designing, planning and implementing a new persistent pain management service.

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## Method

There were three phases to this study:

- a) Identifying typical routes of care for chronic pain patients.
- b) Estimating the number of chronic pain patients in the PCT receiving care outside general practice care; that is not being wholly managed by their general practice.
- c) Estimating the costs of care for those patients receiving care outside general practice care.

### Identifying typical routes of care for chronic pain patients

A previous study commissioned by Tower Hamlets PCT identified departments and services likely to be accessed by chronic pain patients (Mawer, 2006). Potential referral routes were then mapped and linked based on interviews with clinical leads and the service providers involved.

### Estimating the number of chronic pain patients in the PCT receiving NHS care outside general practice

- i) We set up a working group of clinicians, researchers and managers to establish an agreed set of inclusion and exclusion criteria that was appropriate for identifying chronic pain patients. European guidelines for chronic low back pain (Airaksinen *et al.*, 2004), pharmaceutical and clinician experience were also used to develop the criteria. This list was presented at a number of continuing professional development meetings with clinicians for comment and refinement. This iterative process of discussion using multidisciplinary experts, guidelines and practitioner feedbacks enabled us to develop an operational definition of chronic pain used by the lead clinicians to estimate the numbers of patients suitable for referral to the new service.
- ii) We sought to estimate the number of chronic pain patients referred out of general practice care into other services. It was not possible to identify chronic pain patients using existing management data produced by Tower Hamlets PCT; there is no specific coding for chronic pain (this is because it is a condition as opposed to

**Table 1** Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Localised or generalised persistent pain (duration beyond the expected healing period, typically three months), and which has been appropriately investigated, but is causing any of the following:	'Red flags' <sup>b</sup> – musculoskeletal pain requiring further investigation
Persistent difficulty with activities of daily living	Acute cancer pain (other than post-cancer pain)
Failed simple physiotherapy already or unlikely to respond to physiotherapy alone	Patients whose primary problem is a drug or alcohol problem (should be referred to addiction services in the first instance)
Persistent difficulties with psychological or social functioning	Patients with poorly controlled psychiatric illness (should be referred to psychiatry in the first instance)
Repeated requests for medication	
Persistent difficulties with employment (eg, off work for more than three months)	
Pain associated with any 'yellow flags' <sup>a</sup>	

<sup>a</sup> Psychological predisposing factors, eg, depression, anxiety, fear.

<sup>b</sup> Physiological contra-indications needing immediate medical attention.

a diagnosis). Tower Hamlets PCT holds data about overall activity and resource use pertaining to departments, coded diagnoses and prescribing, some of these diagnoses and drugs can indicate chronic health states but these patients may well have other associated problems that would not necessarily mean that chronic pain is their primary condition. Therefore we focused our research on the departments to which these patients were most likely to be referred. These were neurology, orthopaedics, rheumatology, anaesthetics and pain clinic, physiotherapy, occupational therapy and psychology.

We asked each of these services' lead clinician to estimate the number of patients they see per week or month, based on the inclusion and exclusion criteria we set (Table 1). We also asked the approximate number of follow-up sessions

**Table 2** Estimated prevalence of new patients with chronic pain in non-general practice care

Service	% of new referrals who have chronic pain	Estimated number of follow-up appointments
Rheumatology	5	5
Orthopaedics	5.5	5
Neurology	0 <sup>a</sup>	(5)
Pain clinic	90	8
Physiotherapy (musculoskeletal only)	5.5	8
Occupational therapy	4	6
Psychology	0	(estimate 8)

<sup>a</sup> We assume most neurology chronic pain patients were referred on to the pain clinic; therefore we excluded this datum to avoid double counting.

required for these patients (Table 2). We used Tower Hamlets PCT activity data to determine the proportion of chronic pain patients.

The activity data showed general practitioner (GP) referrals, secondary care referrals, new appointments, follow-up appointments and average follow-up ratios.

### Estimating the costs of care for those patients receiving non-general practice care

We estimated cost using two methods:

- Firstly, using NHS national tariff data (Department of Health, 2006) and follow-up ratios. These data are produced by the Department of Health and are determined from data returns acquired nationally via PCTs and NHS trusts, these returns, include for example staff costs, overheads, and costs of interventions and tests. The national tariffs are worked out using number of patients and appointments per costs apportioned to each service.
- Secondly, three of the authors reviewed a 'snap shot' convenience sample of anonymised chronic pain patient case files from one arbitrary session of the pain clinic. We recorded the number of appointments, services experienced, number and type of interventions and duration of chronic pain. We applied tariff and notional costs accordingly. We used the national NHS tariff and reference costings 2006 (Department of Health, 2006) and developed notional costs for other services using London

North and London South electives prices for non-tariff items 2006.

Ethic approval was granted by the East London and City Ethics Committee 3.

## Results

### Identifying typical routes of care for chronic pain patients

Tower Hamlets PCT prioritised the management of chronic pain in 2006, preliminary investigations revealed that the pathway of care for chronic pain patients was complex and that many patients were treated in secondary care and referred from one speciality to another, for example, orthopaedic surgery to neurology to rheumatology and finally the pain clinic (Parsons *et al.*, 2007). We found a very complex referral system with multiple ports of entry into additional care services and complex cross-referral systems between different services (Figure 1).

We did not find any system for tracking patient journeys through the system.

### Estimating the number of chronic pain patients in non-general practice care

We identified 17 542 new referrals into pain, neurology, trauma and orthopaedics, and rheumatology secondary care services in the financial year 2006–07, from the Tower Hamlets PCT adult population of 149 500. Some patients, however, may have been double counted if they were referred to more than one service in the financial year. New referrals into our secondary care services of interest equate to approximately 117 consultations per 1000 people per year.

We estimated that 997 people, approximately 18% of new referrals to secondary care were chronic pain patients, that is, about seven per 1000 per year of the Tower Hamlets PCT adult population.

### Estimating the costs of care for those patients receiving non-general practice care

Table 3 shows the tariff data and estimated costs of chronic pain patients receiving care in each service. Clinician estimates gave the average number of follow-up appointments chronic pain patients may typically have (range 5–8). To check

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the face validity of these estimates we reviewed the chronic pain patient, case notes (13) from one session in the pain clinic. The average duration of care, from the patients' case notes reviewed in the pain clinic, was five years (range one month to 14 years), the average number of consultations received in the pain service was eight (range 1–28), eight patients had been treated by one or more other services, mainly rheumatology, orthopaedics or neurology and often with additional physiotherapy. Interventions exposed to included surgery, injections, blood tests, X-rays, MRI scans and CT scans.

### Cost of chronic pain patients per annum

Following a GP referral, the cost per chronic pain patient per annum, using national tariff data only and estimated follow-up consultations, ranged from £296 to £1120 (the least and most expensive service tariffs). Realistically it would be unlikely for a patient to receive full care from more than one service considering referral waiting times between secondary care services (up to 12 months).

## Discussion

The data presented need to be viewed as estimates because definitive information about numbers of chronic pain patients does not exist. This pragmatic study illustrated that information for making a business case and planning a new service for chronic pain patients within the NHS was limited and problematic.

Due to the difficulties encountered collecting data, scientific rigour was compromised due to practical limitations. These issues and limitations are described below.

### Counting chronic pain patients

We used our operational definition of chronic pain to help clinicians estimate numbers of chronic pain patients in their services. Ideally, prospective studies collecting and coding patients using this operational definition of chronic pain patients would have provided more accurate data, but the resources and time to do this were not available.

Additionally, some chronic pain patients may have been double counted due to multiple referrals as all department data were analysed separately; however, the waiting times for referrals

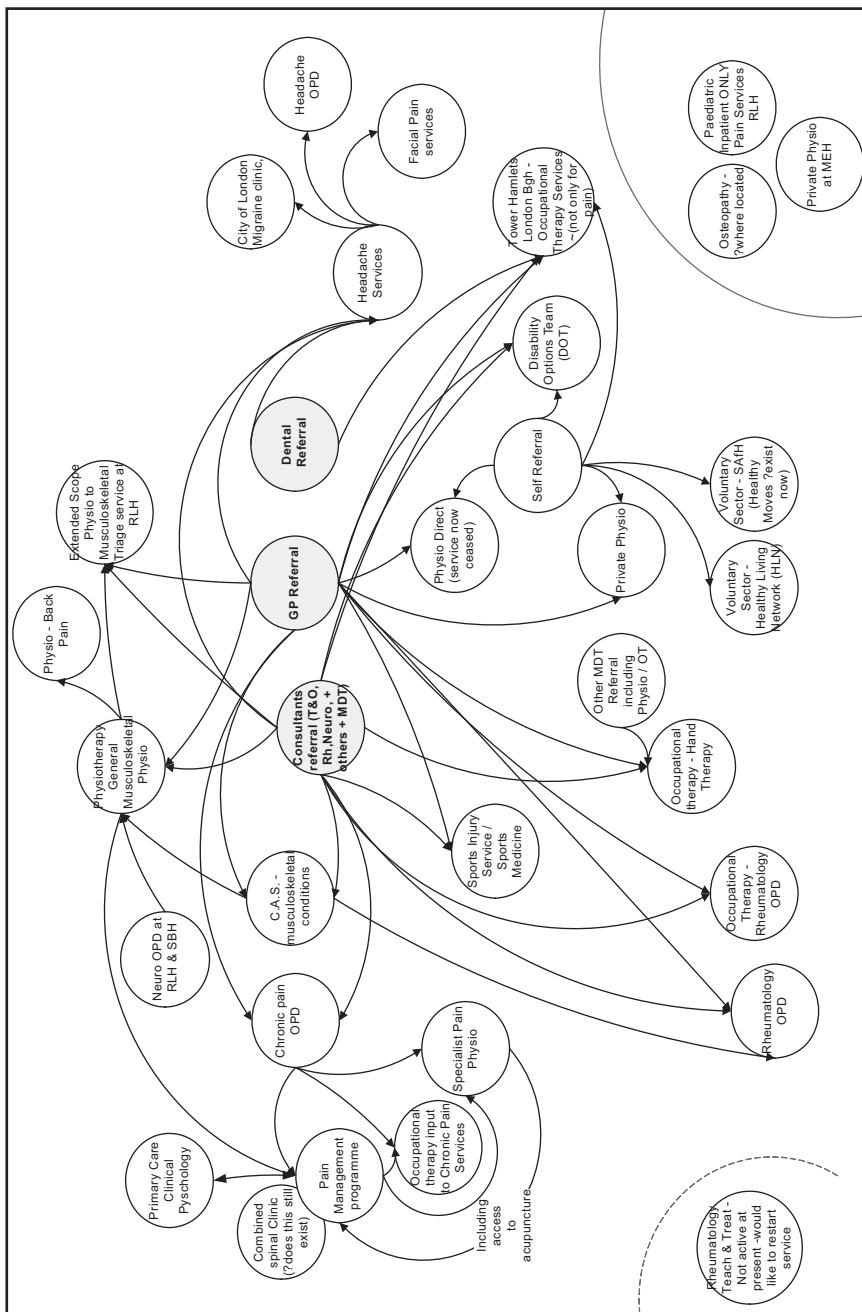


Figure 1 Chronic pain care pathway.

**Table 3** Cost data

Service	1st appointment tariff (£)	Follow-up tariff (£)	Estimated follow-ups	Cost (£)
Rheumatology <sup>a</sup>	224	99	5	719
Orthopaedics <sup>a</sup>	148	73	5	513
Neurology <sup>a</sup>	300	100	5	800
Pain clinic <sup>a</sup>	192	88	8	896
Physiotherapy <sup>b</sup>	48	31	8	296
Occupational therapy <sup>b</sup>	71	50	6	371
Psychology <sup>c</sup>	140	140	8	1260

<sup>a</sup> Using secondary care national tariff figures 2006/07.

<sup>b</sup> Using London North and London South electives data for non-tariff items.

<sup>c</sup> Using average unit costs from primary care reference costs.

between secondary care services were so long at the time that this was unlikely.

Another way of estimating demand for a new service could be based on population data, but this too has its limitations. There is a high reported prevalence of chronic musculoskeletal pain in the community in the UK, it varies from 46% to 76% (Croft *et al.*, 2003; Andersson, 2004; Thomas *et al.*, 2004; Parsons *et al.*, 2007), although only a proportion of these will seek NHS health care (Parsons *et al.*, 2007). Tower Hamlets has an adult population of 149 500 (Directorate of Public Health Tower Hamlets PCT, 2008). Even if a quarter of these end up in secondary care, the financial repercussions may be onerous.

### Unacknowledged costs

The cost data do not include prescribing costs, general practice care or community-based services and social care, our estimates do not present a true reflection of chronic pain patient cost but they may reflect potential costs of care outside general practice care in secondary care. We have used tariff costs as developed by the Department of Health; these include the costs of interventions in each speciality and are based on averages of costs against overall patient data – and in the absence of more accurate data a pragmatic approach is necessary. Our data show that chronic pain patient costs can vary dramatically. A patient who is referred to physiotherapy only may cost about £296, but someone who is referred to physiotherapy, then rheumatology and finally to the pain service may cost a minimum of £1911. These figures do not include the additional cost of the GP (£20 per consultation) excluding

prescription costs (Health Protection Agency, 2006)) or medication.

### Multiple referrals

We know from our study and experience that people living with chronic pain can have multiple referrals, many tests and may receive care over a long duration. Chronic pain patients are, paradoxically, indiscernible due to chronic pain being a health state and not a diagnosis, indicating longevity and complexity.

Chronic musculoskeletal pain can be managed using a coordinated and planned multidisciplinary approach (Flor *et al.*, 1992), but multiple referrals based on trial and error elimination do not constitute multidisciplinary care. The sample of patient case notes reviewed corroborated the complexity of the potential referral pathways shown in Figure 1. Without further research we cannot conclude that our sample of patient notes reviewed were representative of all chronic pain patients but our sample did reflect a clinical session patient case load, which adds, all be it limited, content validity to our mapping Figure 1.

There are many ways of defining and apportioning costs in the health service, generally direct, indirect and opportunity costs are considered (Graham and McGregor, 1997); final figures depend on the reason for doing the accounting in the first instance (Drummond *et al.*, 1987; Graham and McGregor, 1997). This project was undertaken to estimate demand and cost for a new chronic pain service and it illustrates the difficulties investigating health states rather than specific conditions. Our care pathway map shows how complicated it is for a patient to receive care based on a

multidisciplinary approach; it illustrates the potential for delays and loss of continuity and duty of care.

To conclude estimating both the amount and cost of chronic pain patients is difficult due to the problem in identifying them. Once identified, the issue is resolved as patient resource use can be monitored and tracked. Criteria for identifying these patients have been suggested here, and undoubtedly now that this exercise has been conducted, better estimates will advance this study.

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