

## **Somerset Community-Based Self-Care Support Service for Adults with Persistent Pain**

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# 1 Methodological points about case studies

The NHS knows it needs to learn from best practice.

The NHS knows that across the whole service there are a number of very different examples of best practice which the rest of the Service should learn from. The writing of case studies is one method of trying to diffuse best practice.

But however good the exemplar case study is, the case study on its own very rarely impacts upon the speedy diffusion of best practice. This lack of speed in diffusion is partly because the drivers for change within organisations are not strong enough to overcome the reluctance of organisations to go through the pain of change. Without the existence of very strong drivers for change, even a very good case study becomes just an interesting example of how they do things differently and in a different place from here.

We need to rethink how to write case study to make it more likely that the example will be followed by others. In terms of the diffusion of innovation writing a case study is a further attempt to PUSH innovation into other parts of the NHS. To diffuse innovation properly there needs to be some more pull drivers.

This case study as with all others will contain a narrative about what changes the main innovator made in order to create the innovation. Its a story of change and how it is led. However as with all successful innovation there are a number of resources that were organic to this particular example of change which proved to be vital to its success. Every case study has these organic resources that are a crucial part of their success.

In nearly every case of initial innovations the change has come about because of the drive of a very individual leader. Over time they have worked to overcome the many institutional barriers to innovation using a lot of intuition and drive. This will be crucial to creating the original innovation, but makes straightforward replicability very difficult since these individuals mat not exist in exactly the same way across the NHS.

The power of a single individual leader makes it much more difficult for the copier of a case study to replicate the original.

Therefore after the narrative about the case study we want to outline what the important organic resources were in the case study and try and explain how these resources might be obtained non organically from those that may want to replicate the case study.

## Case studies and integrated care

There is a great deal of discussion about integrated care in the NHS at the moment. This case study is a specific example of how very different parts of a care pathway can be integrated through a main contractor which is itself responsible for the integration. We are exploring this example because it

demonstrates how care can be commissioned and then delivered through a single accountable part of an organisation who then takes the responsibility for integration.

For integrated care to happen there needs to be a strong integrator who will take responsibility for the integration of the care. Usually, as in this case, they will also be involved in delivering some of the service, but they will have the primary responsibility to that patient of ensuring that integration takes place.

## 2 The Somerset support service for adults with persistent pain

Somerset pain management service is a single organisation that contains within it a wide variety of different kinds of services which are organised into an integrated pathway. In most places in the country these NHS services, if provided at all, are provided from separate kinds of provider and care organisations. This means that the difficulty of integration of very different service is left to the individual patient to negotiate.

Stringing together the complex and fragmented services in the NHS into a coherent integrated pathway is a hard task for a patient. It is an even harder task if that patient is in constant pain. Whilst many argue that patients need 'care co-ordinators' or 'care navigators', perhaps this is only the case because many services have evolved over time and have become (at least) cumbersome or (at worst) fractured and unfit for purpose.

The aim of the service is to enable adults who live with persistent pain, to understand and come to terms with their pain, and to adopt strategies for living, which allow them to lead as fulfilling and independent lives as possible.

These aims of the service are achieved by service users gaining good *health literacy*, becoming *activated* and being supported to better *self-manage*.

The service has four main components:

- The clinical service
- Training and support
- Access to peer group support
- Online support and signposting

It is significant that a service that is run by clinicians and that is provided for NHS patients with NHS funding has three other components alongside the clinical service. There is recognition that on its own the clinical service cannot achieve the goals of helping people with long term pain to lead fulfilling and independent lives.

To achieve that, the clinical service needs to develop alongside it a number of other interventions. This means that the contract for the service covers a number of different services which need to work alongside the clinicians providing the prime clinical service. The clinician therefore acts as the accountable prime provider and has to ensure that the very different services around training, peer support and signposting are fully integrated with the clinical service and work to an agreed set of principles.

The point is that the clinicians providing the clinical service recognise that the efficacy of their service will be limited if these other strands of work do not take place successfully:

- If local health care practitioners are trained in better pain management this improves the quality of pain management at a population level

- If patients have the skills and capacity to support each other this improves the longevity of the impact on those patients considerably
- People with pain who become 'expert' continue to work with the service to continually co-design internal systems and processes

At the moment the accountable prime provider is provided and organised through the hospital that employs the clinician.

The four services are detailed below.

## 2.1 The clinical service

The clinical service provides the following main functions:

- Accepting and processing referrals for service users who meet the referral criteria and who have opted to work with the team
- Providing a full assessment of the service user's pain: the cause and associated effects on psychological, physical and social functioning and wellbeing
- Providing up to date, relevant information about the service user's pain and treatment, support and self-management options available to them
- Collaborative personalised care planning with service users according to DH best practice guidance; involving discussions regarding the following options:
  - Access to other services such as community physiotherapy and structured exercise programmes
  - Specialist injection therapy (arranged with an appropriate provider where required)
  - Medication reviews (conducted according to 2009 NICE guidance re: concordant interviewing)
  - User-led Pain Management Programmes
  - Intensive psychologist-led Pain Management Programmes
  - On-line self management programmes with telephone coaching support
  - One to one support through motivational interviewing
  - One to one intensive support from a psychologist practicing cognitive behavioural therapy
- As an exception, the consideration of the need to be referred to an inpatient pain management services and arranging this with an appropriate provider where required
- Referring service users on promptly where other pathologies suspected
- Facilitating discharge through a shared decision making format
- The collection and collation of service utilisation, effectiveness, safety and patient experience data

## 2.2 Support and training

The service provides an ongoing and rolling training programme for GPs and other front line staff which aims to increase the knowledge and skills of these staff in supporting service users to confidently manage their persistent pain. The training programme covers the following:

- A key aspect of the training is to develop service user perspectives
- Definitions, myths and misconceptions about persistent pain
- The cost of pain to individuals and the health economy
- The importance of service user empowerment, activation and self-management
- An overview of the Somerset model of care, the new service and how to access it
- Optimal analgesics
- Specialist injections and the Somerset Clinical Consensus on the use of injections for long term pain
- Case Studies
- Sources of further information

The training programme stresses the generic principles of optimal pain management of relevance to working with people with other Long Term Conditions

## 2.3 Access to peer group support programmes

In light of the evidence base and the feedback from services users, the service supports service users to attend a pain management group work programme, for example the Expert Patient Programme.

The Expert Patient Persistent Pain Programme (PPP) is a self-management course for people living with day-to-day persistent pain. The course, through a process of discussion, peer support and supported goal setting and action planning helps participants learn how to deal effectively with the challenges of living with daily pain. It is delivered by trained and accredited tutors living with persistent pain themselves who have become confident self-managers of pain. The programme is run over six weekly sessions each lasting three hours and is accompanied by a comprehensive and easy-to-follow handbook that deals with areas covered in the course such as:

- Overcoming common misconceptions, fears and beliefs about pain
- Acceptance and taking responsibility
- Pacing daily activities
- Stretching and exercising techniques – where to begin
- Keeping a pain diary and tracking your progress
- Dealing with set backs

The service ensures that service user feedback about the programmes is collected and that this is used to inform the ongoing development of the programme.

Patient activation (knowledge, skills and confidence to self manage) is a primary outcome measure which is collated before and after the programme.

12 peer-led programmes were run over the financial year (2011/12) with 145 service users joining the programmes that ran across 4 localities in Somerset. Feedback has been almost universally positive:

*"Just getting here every week has been good for me."*

*"I would like to say that I thought the course was great and I came away feeling much more in control of what is happening to me. I cannot thank the EPP enough."*

*"Getting to know people who have constant pain makes one realise that others feel anger and frustration too. I found myself admiring the courage of others. I learned a great deal both from the lecturers and also from observing how others deal with persistent pain."*

### **3.4 Online support and signposting**

There are many advantages to joining a group programme. A specific benefit is learning how to manage pain from other people who are already managing (so-called 'social modelling'). There are also disadvantages:

- Not all service users want to join a group
- The waiting time for a local programme can be many weeks
- Costs averages £300 per person who attends the programme
- Skills attrition; the knowledge, skills and confidence to manage pain tend to erode over time unless support is ongoing

To mitigate against these disadvantages, the service also offers:

- An on-line self management programme ('Pathway through Pain')
- An on-line 'personal organiser' ('Know Your Own Health') which is given to people to use whilst working with the service and after they have chosen to be discharged. Know Your Own Health contains a number of elements:
  - A curated web-browser that helps people find personalised information about managing pain
  - A local service directory- updated by service users
  - Personal 'trackers' to support people to track and maintain progress towards goals
  - A social networking site- for people with pain in Somerset
- A structured support group, closely allied to Know Your Own Health<sup>1</sup>, but also offering the opportunity for ongoing face to face contact and *structured* lay-led support

Pathway through pain can be found on the web at [www.pathwaythroughpain.com](http://www.pathwaythroughpain.com)

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<sup>1</sup> <http://kyoh.org/>



### 3.5 How does the care pathway work?

The main stages of the care pathway reflect the need for the service to provide the minimum level of focus and specialism needed to adequately support service users to become activated and to self-manage.

People referred to the service are likely not to have benefited from a medical/surgical-based management approach because either they have:

- a painful condition but there isn't an underlying, medically or surgically treatable cause  
*or*
- a painful condition that fits within recognised diagnostic criteria, but the diagnosis is that of a primary pain problem and the treatment is analgesics and/or self management  
*or*
- a painful condition that fits within recognised diagnostic criteria, but they still suffer pain despite optimal medical management  
*or*
- a painful condition that fits within recognised diagnostic criteria, but the risk of medical/surgical management outweighs the possible benefits and they have made an informed decision to undergo self management support

### 3.6 The focus of the service

The focus of the pain management service is to support people to manage daily pain for themselves by:

- shifting the emphasis from treating an underlying diagnosis to both treating the pain itself and mitigating the effects of the pain on physical and psychological functioning
- supporting service users to actively contribute to the development of their own care plan and to put in place optimal self-care strategies for coping with the pain and maximising their functioning, independence and quality of life.

## The pathway

- As the service develops the referral criteria are being extended to ensure that the hospital consultant, GP or community staff ensures that the person with pain has made an informed decision about analgesic usage and is offered a self management manual, for example The Pain Toolkit or an on-line Pain Manual, prior to discussing onward referral.
- Onward referral can then be discussed if the person with pain feels they need more intensive support than that afforded by using evidence based analgesics and the pain management manual alone.
- The informed decision to enter the specialised pain management service should be made by the person with pain, as a result of a discussion with their hospital consultant, GP or community service and only after reading the 'information for people with persistent pain' booklet which outlines the specialised service on offer.
- A referral is made to the service via the Choose and Book system and a mutually convenient time and location for an initial appointment is agreed with the service user.
- The service user attends for an initial appointment and an assessment is commenced.
- A Care Plan is discussed, agreed and drawn up in partnership with the service user.
- The Care Plan is implemented i.e. optimal analgesics and self-management with additional support from the service where required
- The Care Plan is reviewed in partnership with the service user
- The service user is referred to other staff within the service (eg psychology services) as is required, and only after the decision to work with other members of staff has been shared
- The service user is discharged from the service or referred on to another healthcare organisation as required
- Discharge information, as appropriate, is sent to the service user with a copy to the referrer
- Information is shared with other professionals or relevant others as is required and in accordance with the service user's informed consent
- Carer and family members are involved, in accordance with the service users expressed permission
- Service users are provided opportunities to share their experiences or provide mentoring for other people living with persistent pain
- Appropriate record keeping and data collection is conducted at all stages

## 3 The Components that make this work

### 3.1 A single structure to organise delivery

The hospital has allowed the clinical leader of the service the leeway to work with commissioners and service users to construct the entire service according to a core set of agreed principles. The clinician then makes a case to be allowed to develop the entire integrated service under the auspices of a single provider - the hospital itself.

The service is legally a part of the hospital even though the different elements of the pathway are support structures and services that are clearly non-clinical as well as clinical. Many of these services have been procured from external providers. To create real integration of the patient pathway it is necessary to confront and change the existing silos that deliver existing care and for an organisation to take charge of that integration rather than expect the patient to do so.

With the full support of the hospital and the local commissioners, the pain management service has developed a new organisational form that is itself a challenge to the traditional silos of different forms of care. This is a hospital organised service where clinical care is only one of four very different aspects of the service.

### 3.2 This is the results of 4 years of working together through different iterations

Developing a radical new way of working within the NHS is not an easy or straightforward task. There are very strong cultural forces in favour of carrying out health care in the way it has always been carried out. For those reading this case study with a view to gaining lessons for themselves, one of the most important is persistence.

It is very unusual for the NHS to agree with a radical new way of working first time around. Even though you as an innovator are convinced of the clinical and economic side of your case, it is likely to involve radical change for a number of parts of the system. Often the first or second iteration meets with a “no”.

Even more unhelpfully occasionally the first iteration of the radical change you want to make meets with a yes. But the “yes, go ahead and do something different”, is supplemented by the proviso that you can do this radically different activity, but the status quo in every other part of the system must not be disturbed. This may sound good, but in fact will mean that the innovation will only rarely impact at all upon the wider system.

So, one of the main lessons from this case study is that the innovator must try and make the case over and over again and be prepared to make that case again and again.

Persistence over time is imperative. Change within a powerful system needs constant iteration to find the way in which this innovation will actually work.

Of course, many persistent people do not get results. It may be that they are deluded, make their case in a way that doesn't hit the mark, or they could just be plain wrong. It is important that persistence is associated with a clearly articulated case for change, a willingness to engage in constructive negotiation and an understanding that change takes time and above all *will*. A critical - and often overlooked - element of developing and delivering a change strategy is *building the will for change* across multiple constituencies.

### **3.3 Developing an overall budget for a new integrated service**

The recent method of funding secondary care through payment for each activity of episodic care has created, across an entire pathway, perverse incentives for individual providers of care. The development of the Accountable Lead Provider model gives the provider the opportunity to develop very different financial incentives across the entire patient pathway. Therefore it is vital to ensure that the system of financial rewards within the integrated care pathway is generated in a very different way from those that currently work against integration.

The clinical lead worked with colleagues, service users and commissioners to develop a 'map' of interventions across the care pathway and to describe an 'ideal pathway' from the perspective of the service user. Disinvestment in low value interventions and investment into high value interventions were clearly described as a set of key performance indicators, subject to annual review. The commissioner agreed a capitated budget for the first 2 years of the new service, subject to performance review.

18 months into the transformation, all KPIs are on track, disinvestment in low value interventions has progressed satisfactorily and on a base budget of £1,000,000, over £250,000 has been saved. 20% of this is 'real saving' and the rest has been re-invested in high value interventions; namely on-line services and group and peer-peer support.

The system of financial incentives *within the overall programme budget* is an essential part of this innovation.

It is important to recognise that pain management is a specific service that cuts across very different social and medical aspects. However, what has been achieved in the service is of relevance across all long term conditions.

### **3.4 A governance structure that ensures the patient experiences full integration**

At the moment this service is provided from within the hospital structure and involves a very wide range of services. In most other settings these very different services are not provided from within the same organisation. Successful integrated care needs strong integrated Clinical governance and this is harder than it should be to achieve.

Each institution that delivers care must have strong clinical governance. Over recent years this has improved a very great deal with boards asking more and more questions about their institutions capability to ensure safety and quality.

But care that is genuinely integrated has to unscramble these and recreate them for their new service. They need to be able to report into these institutional clinical governance structures, but must also be able to clinically govern their pathway.

This needs organisational skill and drive as well as a respect for the institutions that you are working with. Accountable organisations that want to deliver more integrated services should ensure that they develop governance structures that support integration.

## 4 Lessons from the Somerset pain clinic for others

### 4.1 Medical leadership

The clinical leader of this service has played the main role in developing the integrated pathway. People who live with long term, disabling pain are usually referred to a secondary care pain clinic. It is therefore difficult to see how, at the moment, such a service could be developed by a medical leader who is not a secondary care clinician. Fellow hospital consultants from a wide range of different parts of the hospital have to, if they are going to refer their patients, grant strong validity to this new pain service. For some of them this will involve them for the first time in referring to self-management courses and they are only likely to do this if they trust the main point of organisation of the service.

However, for the pain service to have the full range of different services to integrate the lead clinician must also understand the absolute necessity of the very different services that make up the pathway as essential to high quality care and support. They must recognise that for most people with pain, for most of the time, pain is experienced not in the hospital but at home and in the community. Therefore it is those locations that must be a part of the integrated service.

This needs an appreciation not only of inside to outside integration (from inside the hospital to outside the hospital) but much more crucially, of outside to inside integration (from the community into the hospital). Such a jump is not easy for a clinician who has spent most of their professional life in the hospital.

The clinician – because they are a clinician can then play the major integrating role in the whole pathway.

It is important that the Accountable Lead Provider model of integrated care has clinical leadership that can gain the legitimacy from the whole pathway. The existing fragmented nature of care is in part fragmented because of the different clinical approaches to care.

There has not traditionally been a strong bond of empathy between secondary and primary care. It is essential that the clinical leader recognises this and can both work with credibility in their own setting and in all the others that constitute a pathway.

Setting up and running a clinically led integrated care organisation must mean that the clinicians are going to have to lead secondary care clinicians and other medical staff. Before any of these iterations of care models had happened, the lead clinical team had been working across traditional care boundaries and had experience of working in integrated teams. The mix of both primary and secondary care clinicians coming together to lead a new organisation gives a powerful recipe for success.

Whichever type of clinician leads a core provider for integrated care, that organisation is going to have to either employ or develop close relationships with other forms of service provider. It is important that there is real trust and 'followership' from other clinicians.

This cannot be short circuited and if it does not exist organically, time and effort needs to be put into developing it. Clinicians need to have a shared vision of integrated working that spans traditional care organisations and boundaries.

## **4.2 The importance of recognising the contribution that patients can make to their own well being**

Pain is a very challenging experience for patients. For many people it is there all the time and can define their lives and what they can achieve in their lives. Over a year a person in pain will have over 6000 waking hours living with that pain.

It is likely, unless they are very ill indeed, that they will have less than 20 of those hours in contact with the NHS. What they search for in those 20 hours is real tangible help in living well with pain for the rest of the year. If the NHS in those few hours can help to improve the capacity of the patient to make their lives of living with pain easier, then there needs to be a full appreciation of the impact that patients can and do make to their own healthcare and well-being.

This is a very different model of care from the traditional NHS model. It recognises the salience of the patients work at self-management of their condition and it recognises that the role of the NHS service is to increase that capacity.

People with long term conditions spend most of their lives self-managing their long term conditions. At the moment, we know that perhaps 50% of people with long term conditions have high levels of knowledge, skills and confidence to self-manage, and about 25% of people have no or very low levels of knowledge, skills and confidence.

NHS services need to recognise that their most important role is to improve the capacity of patients to self-manage so that the people who live with long term conditions are in charge of their lives- not the conditions.

## **4.3 The development of integrated care models over time**

This is a case study about a model of integrating care which would otherwise be fragmented. We are using this as a case study that has been successful both in terms of working with service users to deliver high quality pain management for people with pain, but also to develop for the NHS a better value for money service.

In 2012 everybody in the NHS is talking about the importance of integrated care, and when it was finally passed the Health and Social Care Act of 2012 laid a duty on every part of the NHS to 'promote integrated care'.

Whilst we are not saying that this model of integration is the only one, we will waste significant resources if every locality, for every condition, has to find their own pathway for integration. We do not have the luxury of that time.

What needs to happen in the locality is that time and a lot of effort needs to go into developing much better relationship and the models need to be picked up from elsewhere to make those relationships work.

The NHS cannot 'afford' for every locality to spend 5 years working through different models to get to the full integrated care model - we cannot afford a rash of 'pilotitis' - so it may not be possible to organically wait for this decade of development.

However if that time cannot be spent learning to work together there needs to be time and effort put into the relationship building that would ensure successful integration in the future.

#### **4.4 It is necessary to construct an overall budget for a service which has up until now been provided disparately**

It is really essential for the core provider and the commissioner to develop a better and better understanding of what the existing cost base is for the whole pathway. This is not a straightforward process and may take several iterations to get it right. But it is vital to be able to know how much is actually being spent in order to reshape the service within the existing cost envelope.

Importantly, this way of working is entirely alien for many commissioners and financial directors. The principle of giving clinician autonomy to move money around a system which sits outside the traditional PBR model might be seen by some as a high risk strategy. The keys to making this work were specifically:

- Strong commissioning and clinical leadership
- A commitment on behalf of the commissioner and the clinical lead to building consensus amongst *all* stakeholders before the go-live date
- Mutual agreement on stretching financial and quality KPIs with annual reviews on progress
- Inbuilt financial incentives for the clinical team (80% of money saved to be re-invested)

Across the NHS there are better and better costings for each part of the service, but there are few examples of where this has been fully worked out. The year of care project has some real experiences of it.

The needs to be a real move away from the perverse incentives of payment by results which reward discrete multiple episodes of care towards a system that rewards better value across a programme of care for a defined population



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