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## Introducing the Q Lab and Mind

The Q Lab – part of Q – provides opportunities for individuals and organisations to collaborate and make progress on complex challenges that are affecting health and care in the UK. To do this, the Q Lab convenes people with expertise and experience in the topic.

### [q.health.org.uk/q-improvement-lab](http://q.health.org.uk/q-improvement-lab)

Q connects people who have improvement expertise across the UK and is delivered by the Health Foundation and supported and co-funded by NHS England/Improvement.

### [q.health.org.uk](http://q.health.org.uk)

Mind, the mental health charity, provides advice and support to empower anyone experiencing a mental health problem. Mind campaigns to improve services, raise awareness and promote understanding. Last year, through a network of 125 local Minds, 396,000 people received support in local communities across England and Wales.

### [mind.org.uk](http://mind.org.uk)

Between September 2018 and September 2019, the Q Lab and Mind worked in partnership to **explore how care could be improved for people living with mental health problems and persistent back and neck pain.**

# Foreword

## What are service principles?

Principles are a common way to bring attention to what is important when making decisions about how to design a service.<sup>1</sup> They are widely used in design to create a shared understanding of what is important, and help guide decision-making, between different groups of people using and delivering a service.

## Why create service principles?

These service principles have been created as part of the Q Lab and Mind's work to understand how care could be improved for people living with both mental health problems and persistent back and neck pain.<sup>2</sup>

Mental health problems and persistent back and neck pain are significant issues affecting the health of the UK population. Our work has highlighted that the interrelationship between the conditions continues to be not well known and understood. This affects how people experience mental health and persistent pain, and the support that is needed from health and care services.<sup>3</sup>

These principles therefore aim to highlight what matters to people living with both conditions, to support health care professionals to work collaboratively with them and others to translate this into practice.

There are five principles in total, which carry the insights and stories we've heard from people with lived experience.

Our research tells us that care will be better if these principles are kept in mind when people are designing and delivering services. We recognise that it won't always be easy for health professionals to do everything that is described – and some may seem to be unrealistic at the moment. Our intention is that by sharing this rich learning as service principles, they can be used by people delivering, designing and commissioning services, and the experiences and issues that matter to people most are front and centre of decisions about how to improve care.

## How they were developed

The Q Lab and Mind undertook collaborative research to develop these principles. This began with in-depth interviews conducted by peer researchers with people living with mental health problems and persistent back and neck pain. The emerging themes were used to draft the principles.

Thirty Lab participants developed and refined the principles and a small working group of eight participants then reviewed and gathered further feedback.

This was followed by a focus group of six people with lived experience to give feedback on a more developed version of the principles. Quotes from people involved in this work are used throughout to bring the principles to life.

*Jo Scott and Dominic Burton*

# Service principles for providing care for people with both mental health problems and persistent back and neck pain

*These principles are interconnected and equally important.*

## 1. Cultivate enabling relationships

Support people to develop knowledge, skills and confidence to take an active role in their own health and care.

## 3. Learn together and build a shared understanding

Learn more about the interconnection between mental health and persistent back and neck pain and how it affects an individual to enable shared decisions.

## 5. Collaborate across services and agencies

Work together and share relevant information.

## 2. Understand and cater to context

Understand people's background, their support network, and other things in their life that are important and may influence an individual's decisions, experience and ability to support themselves.

## 4. Jointly explore risks, options and expectations

Explore which options are likely to be most helpful and jointly consider the risks (acknowledging that taking risks can be a positive step). Try different things to find what works.



# The service principles



## 1. Cultivate enabling relationships

As with other long-term health conditions, most of the time, people living with mental health problems and persistent back and neck pain manage their own health and care, often with support from family and carers. Relationships with health care professionals often play a significant role in enabling individuals to do this. Relationships should recognise people’s ability to support themselves – and others in similar positions – and enable them do this well. This is likely to include supporting people to develop knowledge, skills and confidence to take an active role in their own health and care. Trust, being believed and empathy are the foundations of good relationships.



“[On a good relationship with a GP] It was her capacity to understand where I was and give the power back to me... to say you know what is best for you and I will support you and facilitate it, [that made helped me].”

“I really like physio because you have 30 or 40 minutes of someone’s time... they talk to you and they listen to you while they’re doing things. You just have their time. They listen and they help you.”

“Advice like, ‘lose weight’ can seem patronising if the person giving it doesn’t take the time to understand the barriers to doing this.”

How health professionals can enable this in practice	Most important...
Build in time to ask questions, listen actively, and be open about what you do and don’t know so you can build a trusting and empathetic relationship.	during appointments
Be mindful of different levels of knowledge, confidence, motivation and ability to change health behaviours and lifestyle. Use plain English and language that is less likely to be misinterpreted.	always
Support people to develop their understanding and confidence to take an active role in managing their own health and wellbeing.	when making shared decisions



## 2. Understand and cater to context (such as family, carer, job, interests)

Living with mental health problems and persistent back and neck pain can impact on many areas of people’s lives, including relationships, interests and work. These are also important factors in staying well. Health care professionals should take the time to understand people’s background; their support network; and other things in their life that are important to them and may influence their decisions, experience and ability to support themselves.



“Most of my mental health support network has come from volunteering at Mind. It was a psychiatric nurse who suggested I do it years ago.”

“I think especially if you’ve got chronic pain and find it difficult to get out, I think it’s a huge support network [online friends]. They’re probably my biggest support network.”

“If people stop talking about what’s wrong with you and start talking about your own inherent possibilities to help yourself, behave differently and live differently, that is a much more positive approach.”

How health professionals can enable this in practice	Most important...
<p>If this is the first time you have met the individual, aim to understand their story and take into account their past experiences with health care services and professionals. They may have explained it many times before, so they will appreciate it if you have already learned from their notes in addition to being given the time to tell their story in their own words.</p> <p>Understand the hopes and ambitions people have for the future and work with them to set goals.</p>	<p>when meeting for the first time</p>
<p>Provide opportunities for people to involve their carers and family members in appointments, decisions and planning for care. It is also important to consider what kind of information and support their carers and family members will need.</p>	<p>during appointments</p>
<p>Encourage people to reconnect with or adapt interests or volunteer activities they may have set aside, or to continue with the ones they have. There can be a period of adjustment or loss as relationships, work or interests can’t be pursued as a result of the changes in their health. People may benefit from peers support through this adjustment.</p> <p>Jointly consider what support people may need at work, and where and how they can get the support they need.</p> <p>Consider interventions and support services that address the things that matter most to that individual. This may include relationship counselling, or information on sleep, nutrition and physical activity.</p>	<p>when making shared plans</p>



### 3. Learn together and build a shared understanding

Learning together about the interconnection between mental health and persistent back and neck pain, and how it is affecting an individual, is important to enable shared decisions about which interventions and support are more appropriate for that individual, their family, friends and carers.

It can be a grieving process for people to accept they might not be able to live the life they were expecting. People can still, and do, live joyful lives.



“This week I met a consultant who said he didn’t know about [my pain condition] and was willing to learn about it from me. You don’t have to know everything. When it comes to pain and mental health there aren’t answers in everything. It’s about exploring options, being open about uncertainties.”

“It’s about giving yourself permission that life is different and that that is okay. That you don’t have to be able to do everything that you did before.”

How health professionals can enable this in practice	Most important...
<p>Jointly build and explore your understanding of the connections between persistent pain and mental wellbeing and how it is affecting that individual.</p> <p>Provide people with access to relevant information and education opportunities. Learning from others can be helpful, whether through a course or informally within a network.</p> <p>Be open about uncertainties and what you don’t know; professionals can’t be expected to know everything. If you haven’t heard of someone’s condition, ask them about it. Even if you think you understand the underlying pathology, only the patient and their carers will understand how it is affecting them and their life.</p>	<p>When meeting for the first time</p>
<p>Help people to build on the skills and tools they have to manage their health and wellbeing by offering support and providing opportunities to develop both condition specific and general health knowledge and awareness – including resilience, acceptance, and understanding their limits.</p>	<p>during appointments</p>
<p>Provide people with different perspectives on living with mental health problems and persistent pain and the approaches you and they can take.</p>	<p>when making shared decisions</p>



## 4. Jointly explore risks, options and expectations

Everybody is different and there are many options for how people can be supported and treated. Health care professionals need to explore with people which options are likely to be most helpful. There may be some options that people don't feel ready to do, but might be right for them in the future. It is also important for people to jointly consider the risks of different treatment options as well as health and lifestyle factors with health care professionals, acknowledging that taking risks can be a positive step.

Both mental health problems and persistent back and neck pain are long-term conditions which may not be 'fixed' or cured through treatment or medication. People can, and do, live happy and fulfilled lives with these conditions. For many this comes from trying different things and finding what works.



“Be more confident in yourself. Don't treat [health professionals] like gods. Just treat them as normal people. Be more challenging because it's your care, it's your body.”

“If you're offered mindfulness, pain management or both, take them. Take them and just invest in the process. Take them, do them and invest in them. Believe in them, because they will help you.”

How health professionals can enable this in practice	Most important...
<p>Explore options using decision-aids and accessible information to enable fair comparison.</p> <p>Be honest and open about uncertainties and risks to enable people to make an informed decision.</p> <p>Think about who else a person might want involved in their decision, such as other health care professionals involved in their care, their carer, family or a trusted friend.</p> <p>Take time to understand any barriers to change. Keep an open door as people explore their options, develop their understanding of their health and healthcare needs, and are ready to make changes or informed decisions.</p> <p>When learning something new people may be in shock and need more time than expected to process information before they can make decisions.</p>	<p>when making shared decisions</p>
<p>Be proactive in identifying people with complex needs who may benefit from a different approach.</p>	<p>during appointments and when designing services</p>
<p>Help people to know what to do when there is a significant change in their health and wellbeing, including providing practical plans for 'what if' situations, and to ensure any new issues are taken seriously and they are supported in a consistent way.</p>	<p>when making plans together</p>





## 5. Collaborate across services and agencies

We know that mental health affects physical health and vice versa, therefore it is not enough to focus solely on either one. In order to provide the care that best suits people’s needs, health care professionals with different specialisms need to become familiar with local services, work together and share relevant information.



“Good practice is me, as the patient, being part of a dynamic conversation between those who can manage my pain and those who can support my mental health. Not a series of referral letters and letters to my GP.”

“My experience is I get pushed around to different departments and none of those different specialisms see the whole. GPs are meant to see the whole, but they don’t, they don’t have the time to see the whole person.”

How health professionals can enable this in practice	Most important...
<p>Acknowledge uncertainties and work with the individual as well as colleagues from other specialities to explore different options and be aware of new developments about mental health and persistent back and neck pain.</p> <p>Set out plans for how people can manage challenges when accessing different services.</p> <p>Be alert to the possibility of not giving due attention to physical or mental health problems because of a dominant focus on the other.</p> <p>Being open and talking about mental health and persistent pain can be difficult for many. Consider what training, support, environment and processes are needed for staff to make this easier.</p>	<p>when making shared decisions</p>

## Using the principles in practice

*The service principles describe what matters to people with lived experience of mental health problems and persistent back and neck pain.*

The principles are not aimed specifically at one health service professional group. Nor is there one single way to use them. Organisations will need to decide for themselves how to apply the principles in a way that aligns with their values, operational contexts and the needs of their local population.

Regardless of context, principles can be a useful prompt to use between stakeholders in understanding the standard of care that is provided now, and opportunities for improvement.

The principles were developed through research with people with mental health problems and persistent back and neck pain. Some of the principles may be transferrable to other, similar, long-term conditions. We'd support others to think and explore how they could be adapted.



### Instances where you may find them useful:

#### Designing a new service or making improvements

The principles could be used as a framework to consider requirements for a new service, or improvements to an existing one. Every locality will have slightly different priorities. The principles provide a useful set of themes to explore when undertaking your own research to understand your local needs, for example with service users and staff. The principles provide a set of standards from which you could assess your strengths and weaknesses, and help you identify areas in which you could work together with your service users to shape care to better meet their needs.

“The design of a service considers more than just these service principles, but what they add is understanding about designing a service that is patient-centred.”

Health service design researcher with lived experience

## Commissioning services

When services enter into new commissioning arrangements or are seeking new funding, it provides a useful opportunity to review the components of a service that will ensure people have high quality care. Funding and new commissioning agreements can provide both a 'carrot' and a 'stick' to enable services to work together and try new ways of working. The principles could be used as a vision for identifying or prioritising improvements. They could help to inform decisions about the outcomes and service measures that are important, and highlight the skills and capabilities needed from staff, and additional training needs.

**“Organisations waste money and resources treating a symptom when the whole of the patient experience is ignored [...]. These principles will save money, encourage better care and further the understanding of the patient experience.”**

Commissioner with lived experience



## Patient information and involvement

The principles weren't written to be read or used specifically as patient-facing information, but they could be useful for others living with the conditions as they highlight what others living with the conditions find useful.

**“I think some people [living with the conditions] will find the principles both informative and validating, in addition to providing them with some assurance that their clinicians and services understand the dual nature of their health difficulties.”**

Researcher with lived experience

## Training tool to prompt discussion

The principles provide a useful framework to use in training and skills development sessions to prompt a reflective discussion on what high-quality, person-centred care looks like in practice, and the extent to which their service enables this.

**“I think my experience would have been better had such principles been followed.”**

Focus group participant

# Endnotes

1. 'Service Principles – in Practice: How laying down clear guidelines drives service success'. Touchpoint Vol. 7 No. 1 - April 2015. Available from [https://issuu.com/touchpoint\\_journal/docs/touchpoint\\_7-1\\_preview](https://issuu.com/touchpoint_journal/docs/touchpoint_7-1_preview)
2. Some people living with persistent pain may not identify with having a 'mental health problem' or even meet a formal diagnostic criteria: these principles are still relevant. We know that people living with long-term conditions such as persistent pain are at a higher risk of experiencing common mental health problems such as anxiety and depression, and people living with pre-existing mental health problems are more likely to experience persistent pain than those without. (Read our essay on this topic <https://qlabessays.health.org.uk/essay/mental-health-and-persistent-pain-anintroduction>)
3. Scott J, Keck L. 'Challenges and opportunities to improve: What's been learned about mental health problems and persistent back and neck pain.' Q Improvement Lab. Health Foundation, 2019. <https://qlabessays.health.org.uk/essay/challenges-and-opportunities-to-improve/>

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