Q Lab research sessions

October 2018

Improvement Lab

In partnership with mind for better mental health

Research sessions

In October the Q Lab ran a series of small research sessions, focused on the challenge: *What are the experiences of people living with both mental health problems and persistent back and neck pain, and how can care be designed to best meet their health and wellbeing needs?*

The purpose of these sessions was to draw on the lived experience and expertise of Lab participants, to help shape and steer the Lab's research on this challenge.

The sessions were attended by a diverse group of 25 people. This document is a summary of what was discussed, what we heard and the early themes that are emerging.

Making sense of the outputs

In the sessions, attendees completed activities that helped to surface peoples insights on this challenge.

The discussions generated a lot of content which we wrote up into a presentable format.

To help make sense of the outputs from each session, we've used a framework to collate relevant content from across each of the activities.

This framework separates the content into four categories – problems, insights, needs and themes.

Problems – content that specifies or refers to a specific thing that we think or people have named as a problem.

Insights – content that is an insight and contributes to our understanding of a particular issue.

Needs – content that relates to a particular need of a patient or health care professional.

Themes – higher level issues that started to emerge from the content.

Problems

Problems represent something that we could investigate further in research, validate through research, or use as stimuli to generate potential ideas that address this problem.

There is luck involved in finding the right person - how do we make it systematic?

Some people are not informed of the links between pain and common mental health problems.

Stigma of having mental health problem and being believed when you have chronic pain.

People have often tried lots of different interventions. Many don't help, they might try three pain management courses before they find the one that helps them.

You become vulnerable to people (or solutions) that claim they can cure your problem.

Some people are not willing to accept they have mental health problems that may be key to managing their pain.

There can be pressure to take a medical route – either led by the person living with the condition or the health professional.

Referrals - to refer someone you need a lot of information about them, or to know that what services exist.

Physios often need to use non-working hours to refer someone to another service.

Using scary language like degenerative is unhelpful - degeneration happens naturally to everyone as you age.

Mental health problems and pain are invisible conditions.

Insights

Insights are useful to inform research and interview questions, and can guide idea generation and the way we design interventions in the future.

As a psychologist it has worked best when people are curious to explore what they can do to manage their symptoms and are willing/able to consider a full range of possibilities.

You may design your life around the condition/s.

Best way to be in-patient is to be passive. Best way to succeed in rehab is the opposite.

Connection to identity.

Sometimes life events can lead you to do things that you never thought possible - e.g. risks, different jobs.

Doing (and carrying on doing) activities that bring you joy, even though you have pain, is difficult but important.

The things that help people when you feel unwell are the things in life that generally bring you joy.

There may be a number of myths that exist about what pain is caused by and treatment success rates.

People are often more responsive to a friend, family member or peer telling them something than a health care professional.

An empathetic employer can go a long way.

Insights

Mental health services and physical health services often don't talk to each other, even if they are nearby. A patient's physiotherapist, GP and psychologist may never speak to each other.

Referring is a clinical action, therefore clinicians are responsible for the consequences of this decision.

Sometimes the only place you feel you can turn is A&E if you have been 'passed around the system‘.

Sometimes you just don't want another diagnosis, another doctor, more appointments; stigma makes it worse.

Individuals may be actively seeking a 'fix‘.

A&E may not always take neurological pain as seriously as pain with a direct physical cause e.g. a tear or break.

There is a large variation in the care you might get from a GP (even in the same practice).

People with persistent pain will try almost anything to get rid of it.

Frequently I have seen people improve working with me only to lose all of that progress in the weeks leading up to and following an unsuccessful DWP review.

Snowballing - when you feel unwell this can affect many areas of your life, making you feel more unwell...

Needs

Needs are useful in helping to prioritise the work and will help to frame idea generation activities.

To support people in the acceptance, adjustment and learning process after they experience mental health problems or persistent pain.

To have people take your pain seriously even if there is no physical cause.

To have pain explained to you as soon as possible if you do not understand it.

Support when services continually tell you they cannot support you.

To help people to understand the pros and cons of various treatment options and make informed decisions.

Health care professionals to feel more confident or be supported to talk about areas 'outside' their specialism.

Themes

The problems, insights and needs have been clustered to start identifying themes. Four high level themes are emerging:

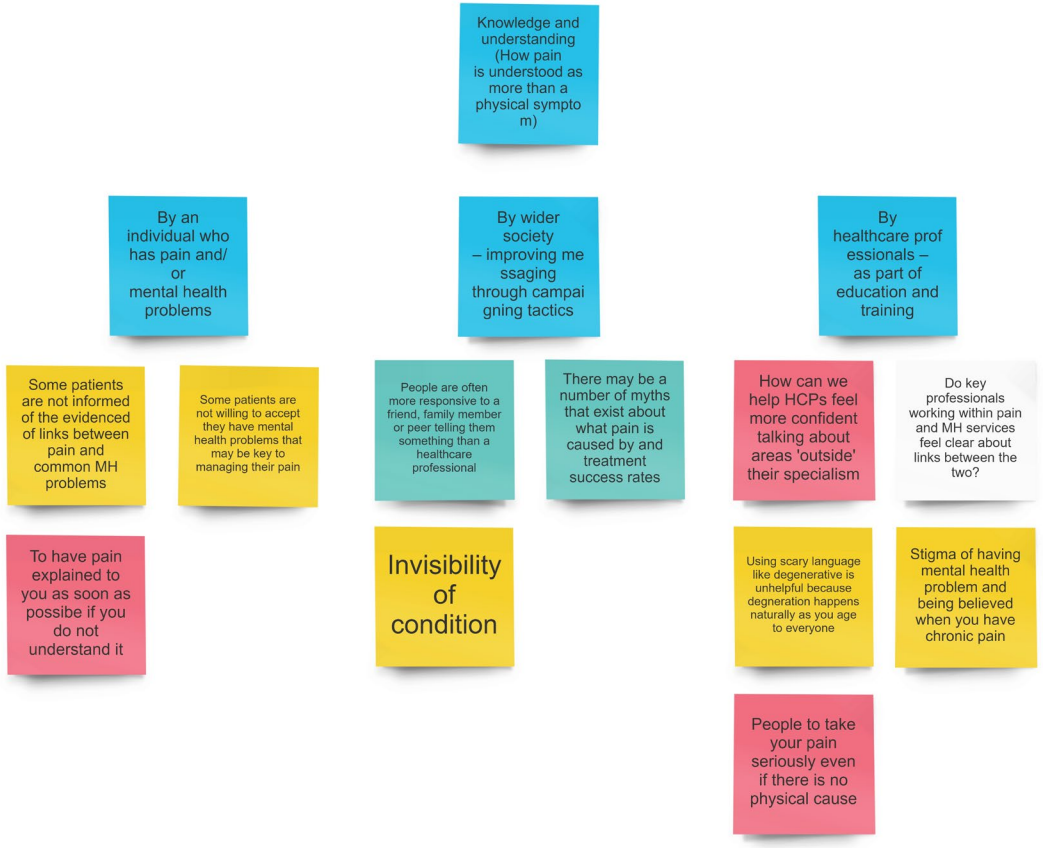
1. **How pain is understood (as more than a physical symptom)**
2. **How the condition changes your life**
3. **Key touchpoints, interactions, actors**
4. **Key points in the journey or pathway**

The following pages describe each of these themes in more detail.

1. How pain is understood (as more than a physical symptom)

There were many conversations around how pain is understood in terms of mental health and physical health. These were grouped according to the following audiences:

- By an individual who has pain and/or mental health problems
- By wider society – improving messaging through campaigning tactics
- By healthcare professionals – as part of education and training



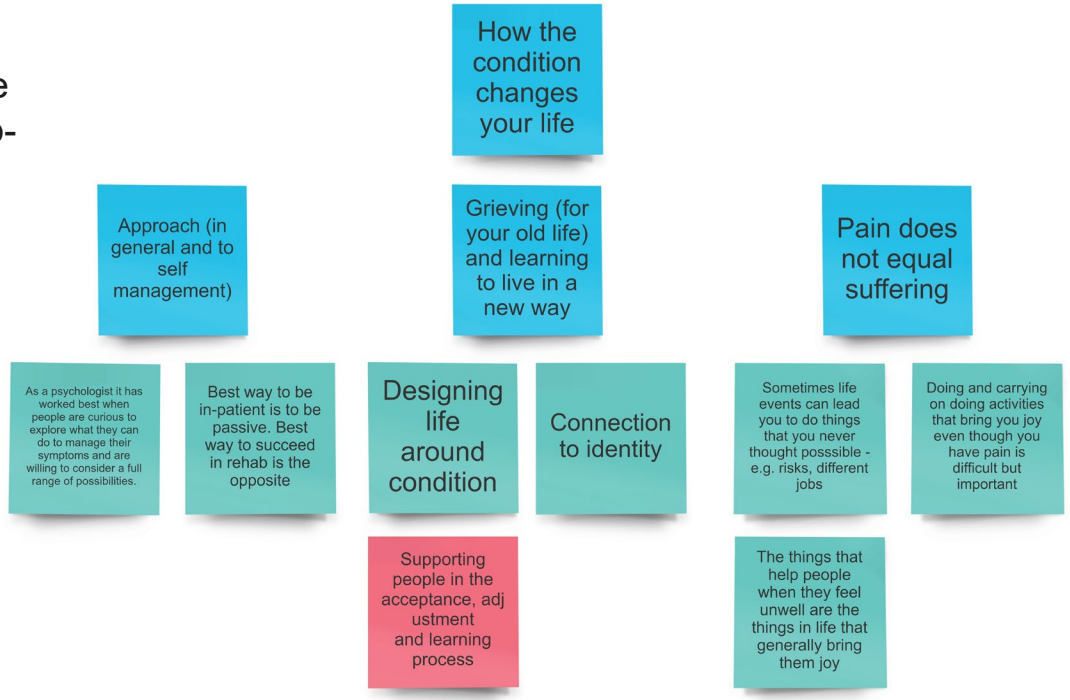
PROBLEMS INSIGHTS NEEDS THEMES

2. How the condition changes your life

This theme emerged particularly during the discussions around what helps people when they feel well/unwell. Three key sub-themes emerged as being important:

- Approach (in general and to self-management)
- Grieving (for your old life) and learning to live in a new way
- Pain does not equal suffering

We will explore these themes more through interviews with people with lived experience.



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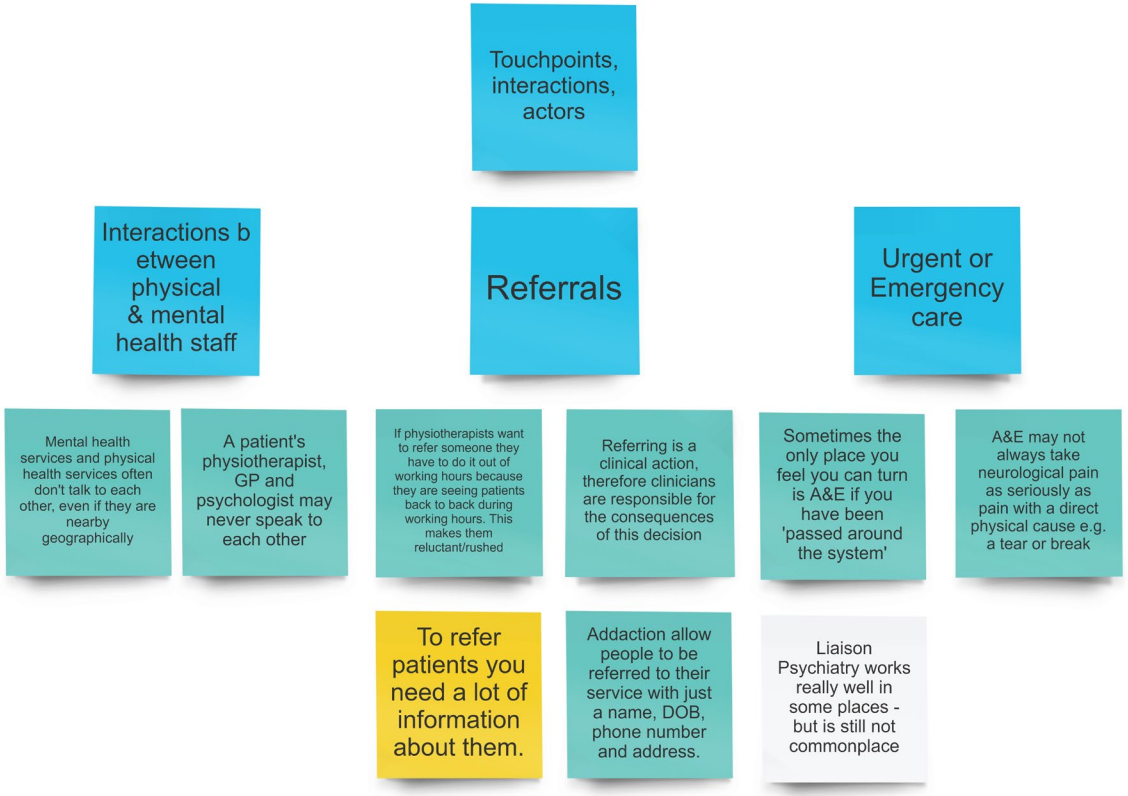
3. Key touchpoints, interactions, actors

Several touchpoints/interactions emerged as being important:

- Interactions between physical & mental health staff
- Referrals
- Urgent or Emergency care

We're keen to explore what other touchpoints and interactions are important.



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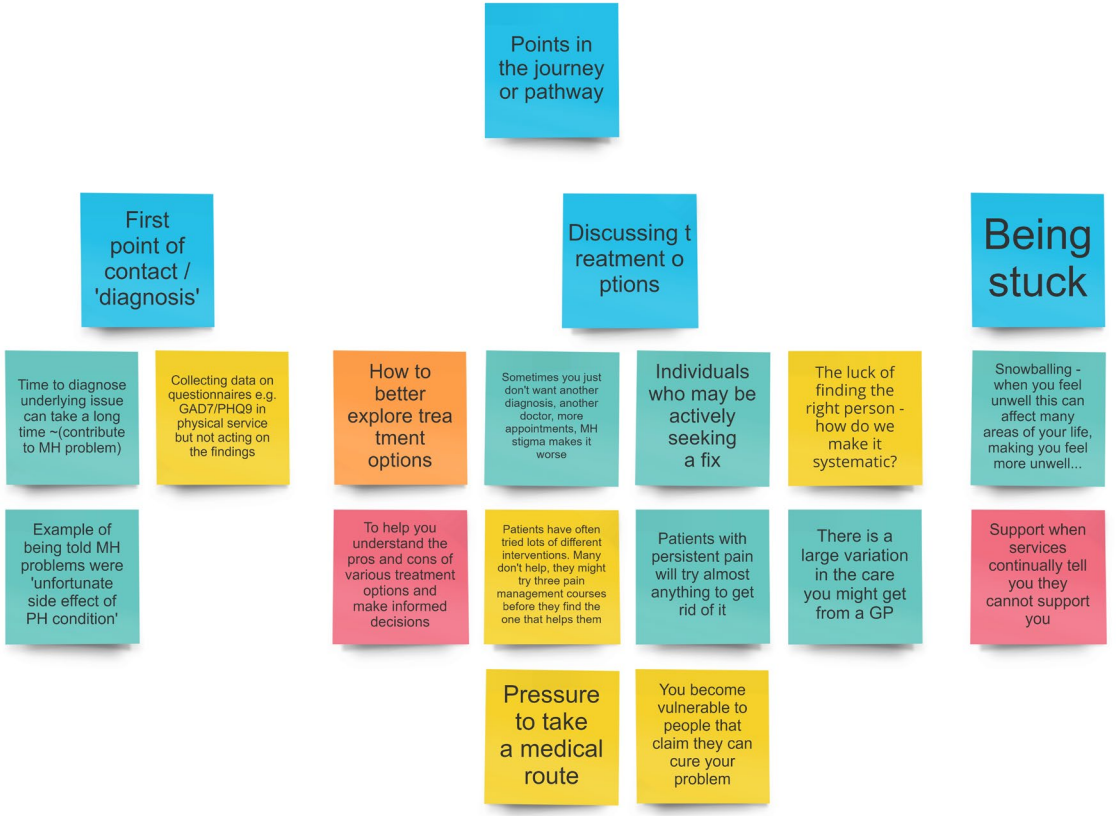
4. Key points in the journey or pathway

There were some particular points in the journey that emerged as being important:

- First point of contact/'diagnosis'
- Discussing treatment options
- Being stuck

We're keen to explore service models and guidelines to better understand 'what good looks like'.



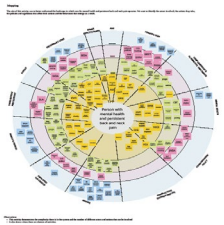
PROBLEMS INSIGHTS NEEDS THEMES

Outputs of activities

You can see the raw content from two activities in the links below.

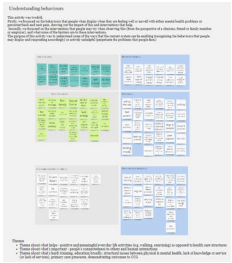
Mapping: understanding the landscape in which care for mental health and persistent back and neck pain operates. We identified the actors involved, the actions they take, the policies and regulations that affect their actions and the behaviours that emerge as a result.

https://public.huddle.com/a/awzryKP/index.html



Behaviours: understanding the behaviours we display when feeling well and unwell, the impact of this and what helps. Drawing out underneath this, our observations on these behaviours with the interventions we might try and the barriers to doing this.

https://public.huddle.com/a/DWNDRyp/index.html



Next steps

The research sessions in October and the initial research survey in September have provided a wealth of information on the issues around mental health and persistent back and neck pain. Over the coming months, research will continue. The aim will be to deepen our collective understanding of the themes that are emerging, so that we can decide where to focus our developing and testing work in the New Year.

Contribute to research strategy

Please do share your thoughts and reactions to this summary document in the Q Lab online group. Do you recognise these themes? Is there anything missing? Who should we be speaking to and learning from in the next phase of research?

https://q.health.org.uk/community/groups/mental-health-and-persistent-pain/

Interested in testing

Are you are interested in working with us as a test site – developing ideas for improvement and testing and prototyping changes in practice? You can find more about what this entails on page 6 of the document below. If you are interested, please get in touch with us at QLab@health.org.uk

https://q.health.org.uk/wp-content/uploads/2018/09/Be-part-of-the-Q-Improvement-Lab.pdf

Thank you

to everyone who joined the sessions...

Adrian Mcgregor
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