

PPI meeting October 2022 - notes and summary

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The link worker project research team and PPI group met in person for the first time in several years (since before COVID) on 25th October 2022. The group shared some lunch and social time. We also worked together on analysis of some early research ideas from the data.

In previous online meetings we talked about the implications or consequences of social prescribing work for link workers. This session was about taking some of these ideas and thoughts, and using our creative thinking to make explanations (or theories) about what the impact might be on *patients*. We wanted to gain a patient/public perspective on these emerging ideas because researchers' perspectives can be limited by their closeness to the data.

Below is a summary of what we did and what we feel were the outputs of the meeting.

Activity one – exploring key ideas

We shared three ideas we have been thinking of as we look at our data and asked PPI members to write down what these words brought to mind. The ideas were: *feedback loops*, *readiness and holding*. We did not give a lot of background to these words to avoid influencing people's thoughts/ideas. We realise this might have made it a bit broad, but that breadth is useful in thinking about what other meanings of these words might be.

Here is a record of what was written by the PPI group on these three ideas:

Feedback loops	Holding	Readiness
Conversation	Keeping something precious 'tight'	Everything in place for moving forward
Questions to answer	Accountable	Be prepared – girl guide
Back to where you started	In your hands	On the start line
Resolution of problems	Keeping still, not moving forward	Anticipation (apprehension or excitement)
Must be precise and honest	Waiting for answers	The final outcome
Can result in change	Not letting go	Positive attitude for change
Well organised	Cattle in a pen	Prepared
Difficult when lots of people are involved	Who is holding? Power in the relationship	Reflected on my problem and ready for change
Lack of coordination	Static – not moving on	Capacity
Missing information – things falling through the net	Holding back	Financial support – fully funded
Two way conversation	Storage	Thought through
Information gathering	Loving	Informed
Group of people talking	Caring	Trained
A process	Supporting	Qualified
Opportunity to share	Carrier bag	Able to start
Discussion group	Cherishing	Ready to go – all set
Governor on a steam engine	Stationary	Open to suggestions
Information to control the process	Results from people not being at ease with themselves	Stage when want to do something
Hysteresis	The bowler's holding the batsman's willy (from a cricket commentary)	How do you get ready?

Feedback loops

The research team had been thinking of feedback loops as communication between link workers and referrers - such as GPs - as well as feedback from services or groups they refer a person into. The broader thinking of the group shows that this is importantly a *two-way conversation* (so the GP giving information about a patient, and the link worker also giving information to the GP about what they are working on with a patient and how the patient is getting on). It is about *sharing* of information. Information sharing is often limited across organisations (e.g. the NHS with the voluntary sector or charities) by their agreements about data protection. However, as shown by what the group wrote, while this might protect patients, it might also be an obstacle to sharing and, therefore, impede *change or resolution of problems*.

Holding

The words the group wrote about this idea reveal there are positives and negatives to holding. On the one hand, holding might be about *cherishing* and *supporting* someone who is in distress. However, it could mean holding someone back, or stopping them from *moving on by not letting them go*. Being *accountable* is interesting. From our patient data, this could be positive for someone who wants to do more exercise or lose weight, as a motivation, but may be negative for someone who feels stressed or pressured. This is, in essence, the dilemma link workers face when working with people who have lots of needs that cannot be dealt with all at once, or who are emotionally vulnerable; do they keep working with them and risk making them dependent, or do they give them emotional support they may not get elsewhere, which might call for a longer term interaction?

Readiness

The group wrote that readiness was to do with being *prepared or making preparations, anticipating some change* and getting *set up* for it. This requires *time* for set up and *thinking*, and a change in mindset or a *positive attitude*. Readiness for change can also relate to *capacity*. The idea of readiness (for doing social prescribing with a link worker) is reflected in our data. Some patients are described (by link workers) as not ready (or to use a health services term not 'activated' enough) for the work that is envisaged as being core to social prescribing (e.g. going to a group or activity, starting a new hobby or exercise regime). However, many people seen by link workers in our study expressed needs for basic or foundational support (e.g. with housing, debt management, food) that they felt were a priority before doing other activities. Does this mean they are less ready? There is something here about the difference between readiness as *willingness* and readiness as *capacity*.

Activity two – explaining key ideas and how they work (theory statements)

We went on to look at some data (quotes from interviews with patients and healthcare professionals) on one key idea – readiness. We wrote some 'if-then-because' statements. In total, 31 statements were written with the group. Here are some of them:

- IF you are feeling low in mood THEN a link worker might help you to move on (be ready) BECAUSE they encourage and motivate you
- IF a person doesn't see they have a problem THEN the link worker needs to read between the lines BECAUSE a lot of people who are down don't ask for help
- IF a person is encouraged to share what they are happy with sharing THEN it may open the door to further help BECAUSE they don't feel pressured to say more than they wish

These statements seem to highlight the importance of time and link worker sensitivity and skills. Link workers may be able to encourage and motivate people to make small changes that lead to more significant ones. However, there is a delicate balance between enabling people to be ready to make changes in their lives and pressuring them. Also, as was emphasised in activity one, some people may not have the capacity for change for multiple reasons to do with their social situation, physical or mental health. We wonder if there is a danger that sometimes lack of capacity might be misinterpreted by healthcare professionals as a lack of willingness to change.

Summary

We have summarised the statements developed on readiness into a theory (explanation) for consideration/comments:

When a person is experiencing low mood, time (for the patient to develop trust, feel comfortable and open up) and link worker communication skills are important for identifying or becoming attuned to where a patient is in their 'readiness' and what their preferences are in how to move forward. Link workers need to understand any barriers, including reasons and fears, which can mean people seem stuck or unable to change. Link workers can potentially encourage and motivate someone according to this appraisal (assessment/judgment), but it is important not to remove the patient's power and agency.

The statements developed by the PPI group enabled us to get into more detail of what potential outcomes may be for patients on this topic of readiness. These could include:

- receiving help and support to be ready to make changes in life that are beneficial to their wellbeing, or

- providing for basic needs that may enable people to achieve further goals (such as social connections or other things like taking more active control of their health).

There are steps along the way to people feeling able to share their problems and open up to a link worker. Holding (continuing to support) people until they are ready can have different consequences. On the one hand, it may make them feel secure and supported and able to share, but it could mean they become dependent on the link worker.

Feedback between those who refer people to social prescribing (usually a GP) and the link worker, as well as the organisations that the link worker refers people into, might help patients to make changes and avoid duplication of work.

Conclusions – areas to explore in the data

It was really helpful to explore our initial ideas from the data with the PPI group; to consider things from a more patient/public focussed perspective. We have refined our understanding of potential outcomes for patients of social prescribing and have made some changes to our thoughts on the study following this meeting. We will further explore:

- Differences in the data on 'holding' in terms of stopping people moving forwards (being static) and cherishing (to build up their confidence to move forwards)
- What our data tell us about how the link worker role has changed in recent years towards supporting people with more significant psychosocial needs (that require more 'holding')
- If, in the data, link workers suggest they are now feeling they have to hold on to patients and their problems rather than referring on to relevant support in the community
- What the data we have collected for the study to date say about the need for the link worker role to be given time to evolve in primary care and take shape (readiness of primary care to deliver and support and sustain social prescribing)
- Whether any data suggest patients were frustrated when referred to a link worker because their role was felt to be too broad (not specialist enough)