An evaluation of link workers in pain clinics

the Health Innovation Network (HIN) South London
September 2023

Health Innovation Network South London

Acknowledgements

The Health Innovation Network (HIN) would like to thank staff members for their oversight and support of the pilot and evaluation, in addition to their valuable insights.

Thank you to the Southwest London team:

- Mohan Sekeram
- Nicola Williams
- Alison Kirby
- Gill Collins
- Theresa Hart
- Amrinder Sehgal
- Emma Croll

St George's University Hospitals NHS Foundation Trust:

- Claire Copland
- Marian Logue
- Irene Campagnolo
- Nikki Yolmo
- Sam Moreno

Epsom and St Helier University Hospitals NHS Trust:

- Zoe Clyde
- Sara Bustamante
- Sarah Hodgson
- Feride Masera

Sincere thanks also to the patients at both sites who generously gave their time and shared their experience of the pilot.

Contents

1. Executive Summary

1.1. Background

The Southwest London (SWL) Pain Clinical Network commissioned the Health Innovation Network (HIN) South London to complete an evaluation of the link workers in pain clinics pilot. This report outlines the findings of that evaluation which ran from May 2022 – August 2023.The Personalised Care Programme in SWL Integrated Care Board (ICB) funded a link worker to be embedded in the pain teams at St George's and Epsom and St Helier hospitals, as part of a 12-month pilot. Specifically, these link worker roles were a health and wellbeing coach at St George's and a social prescriber at Epsom and St Helier. Both roles were patient facing and based at the Trusts.

The purpose of the evaluation was to understand the benefits of and ways to improve the link worker role within pain clinics with the view to scaling up across Southwest London. The service evaluation took a mixed methods approach using: 1) Service and clinical data collected by staff at the pain clinics, 2) Data collected from staff via focus groups and interviews, and 3) Data collected from patients via a survey and interviews.

1.2. Findings

Across the two sites, a total of 74 patients accepted a referral to a link worker. For people completing a survey, a high level of satisfaction was reported by patients who engaged with the link worker, with evidence of a positive experience. It was not possible to collect quantitative outcomes measures for all patients. For patients where quantitative outcome measures were able to be collected, findings indicate that the link worker model of care was of benefit. These findings indicate an overall decrease in the level of patient concern relating to mental, emotional, and physical health. Patients interviewed also reported benefits, such as increased feelings of self-efficacy, positive changes in behaviour and outlook on life.

The link worker model of care was regarded as acceptable and feasible amongst staff, who appreciated this additional role in their team. However, staff emphasised that the link worker role was an adjunct that provided valuable additional support but did not replace the support offer by existing clinical roles, such as psychologists, and physiotherapists. Staff working in the pain clinics were not allocated additional time or resource to fulfil training or development duties that the link worker role required. It was recognised that the recruitment, induction, and ongoing support further stretched their already limited time and capacity.

It was not possible to use quantitative measures to determine any impacts on healthcare provision due to the 12-month duration of the pilot and restrictions surrounding data linkage. Qualitative data suggests that there was no change in healthcare service use, such as reduced A&E attendance. However, staff highlighted that expecting a reduction in healthcare service use was ambitious as this is influenced by multiple factors. A potential benefit to healthcare providers based on survey responses was that patients felt better equipped to 'get the most' out of other healthcare appointments due to increased ability to communicate and advocate for their care.

There were several lessons learnt for implementing the link worker model of care to support improvements, geographical spread, and adoption. Referrals to the link workers were lower than initially anticipated. Referral rates were based on expected 'footfall' within a primary care setting.

Reflecting on the 'lower-than-expected' referral rates, the idea of having a combined link worker able to fulfil health and wellbeing coach as well as social prescriber duties was raised by staff at both sites. The potential for the link worker role to extend to other conditions was also discussed.

Staff recognised that their own passion and enthusiasm for the new model was a driving force for the successful delivery of the pilot. Although they valued the input of the link worker role, they acknowledged finite resources might mean that this post may not be regarded as such a high priority compared to other roles required in a secondary care setting. At Epsom and St Helier, there were challenges due to commissioning arrangements for the pain clinic. Staff highlighted the importance of finding an approach to joint commission the model to ensure patients at this Trust were eligible for the model of care, regardless of postcode.

1.3. Recommendations

1.3.1. Supporting link worker

- Pain clinic services need to ensure that the link worker is well supported to deliver their sessions. For example, providing a confidential space to conduct sessions with patients.
- The link worker should be embedded in specialist teams that are able to provide support and supervision, in addition to providing opportunities for professional development.
- Support should be provided to the link worker to further develop knowledge in long term conditions and experience working within a secondary care NHS setting.

1.3.2. Extending the scope of the link worker role

- Pain clinics should consider recruiting a link worker with existing skills and experience in both health and wellbeing coaching and social prescribing. This will help to broaden the scope of practice and have the potential to increase referrals and rates of uptake by patients.
- Trusts could consider employing link workers across several specialities or conditions. This may help to increase referral rates and ensure that the role of the link worker is best utilised.

1.3.3. Considerations for future commissioning

- Future commissioning should factor in cost and capacity associated with additional tasks required to be carried out by clinical teams hosting link workers such as providing induction and training alongside regular supervision.
- Future commissioning should be aware of and account for restrictions faced by Trusts that are funded by more than one ICB to increase patient accessibility of the link worker model of care in this setting.
- Alternatively, funding solutions should consider employing the link worker through the Trust they are working for. This may overcome the barrier of only a proportion of patients being eligible for the intervention and simplify governance requirements for this role.

1.3.4. Further research

- Future research could examine the impact of this model of care on healthcare service use, such as GP and A&E attendance. This could be achieved through quantitative data linkage processes to track a patient over a longer period. However, it must be noted that this is likely influenced by complex factors. A more suitable metric may be medication

compliance, secondary care service referrals, or a patient's perceived ability to manage their condition.

- Future pilots should focus on increasing referral rates and therefore patient sample size. This would facilitate additional subgroup analysis and provide greater insights on which patient groups are benefiting the most and those experiencing health inequalities.
- To increase the response rate to the question around patient satisfaction, the satisfaction survey could be replaced with single 'friends and family' test question i.e., 'Would you recommend to a friend?'.

2. Background

The Southwest London (SWL) Pain Clinical Network commissioned the Health Innovation Network (HIN) South London to complete an evaluation of the link workers in pain clinic pilot.

Evidence shows that people will have better experiences and improved health and wellbeing if they can actively shape their care and support[1]. Link workers support people to take more control of their lives and unpick any issues affecting their health and wellbeing. The 'link worker' title is often synonymous with roles such as 'community connector', 'social navigator' and 'wellbeing advisor'[2]. The Personalised Care Programme in SWL Integrated Care Board (ICB) funded a link worker to be embedded in the outpatient pain clinics at St George's and Epsom and St Helier hospitals, as part of a 12-month pilot. Specifically, these roles were a health and wellbeing coach at St George's and a social prescriber at Epsom and St Helier. Both roles were patient facing and based at the Trusts.

Social prescribing[3] is a key component of Universal Personalised Care[4]. It is an approach that "connects people to activities, groups, and services in their community to meet the practical, social and emotional needs affecting their health and wellbeing" [5]. Examples of social prescribing include volunteering, arts activities, group learning, gardening, befriending, cookery, healthy eating advice and a range of sports.

Health coaching is a supported self-management (SSM) intervention and is part of the NHS Long Term Plan's [6] commitment to make personalised care 'business as usual' across the health and care system. Health coaching is defined as "helping people gain and use the knowledge, confidence and skills to become active participants in their care so that they can reach their self-identified goals". [7] Health and wellbeing coaches guide and prompt people to change their behaviour, so that they can make healthcare choices based on what matters to them.

The expected benefits of the link worker model in pain clinics included:

- Improved health outcomes for patients who have received all available medical interventions and would benefit from support to address their social needs.
- Reduction in General Practice (GP) and Accident and Emergency (A&E) attendances for chronic pain patients.
- Developing new ways of supporting self-management and linking to community assets.
- Better links between primary care, the hospital pain clinics, and the voluntary sector, in line with the personalised care agenda.
- Opportunity for shared learning and peer support between the pain clinics link workers and the wider social prescribing networks.

---

[1] NHS Long Term Plan » Personalised care
[2] https://www.socialrx.co.uk/blogs/blog/what-does-a-social-prescribing-link-worker-do
[3] NHS England » Social prescribing
[4] NHS England » Universal Personalised Care: Implementing the Comprehensive Model
[5] NHS England » Social prescribing
[6] NHS Long Term Plan » The NHS Long Term Plan
[7] https://www.england.nhs.uk/personalisedcare/workforce-and-training/health-and-wellbeing-coaches/

2.5. Overview of the model of care

2.5.1. Health and wellbeing coach at St George's University Hospitals NHS Foundation Trust

A health and wellbeing coach was appointed to work within the chronic pain service at St George's Hospital. The role was created to support people living with chronic pain to use knowledge and skills to enhance the management of their own health and wellbeing. Techniques used within the role included health coaching and motivational interviewing. These techniques were utilised in one-to-one appointments (conducted either remotely or in person) to empower people to make lifestyle changes to positively impact their quality of life and management of pain.

The health and wellbeing coach received referrals from multidisciplinary team assessments, following completion of a Pain Management Programme (PMP), or via clinical nurse specialist (CNS) follow-up clinics. Referrals were made following a comprehensive assessment and as part of an overall package of care for the patient where there was a clear indication for health and wellbeing coaching input. As part of the referral process, patients would receive reading materials, such as leaflets and posters, with information on the role of the health and wellbeing coach. As this pilot was commissioned by Southwest London Integrated Care Board (ICB), which covers St George's hospital catchment area, all patients receiving care from the Trust were eligible. However, a rationale for a patient referral to the health and wellbeing coach was required which included believing the patient was able to engage in a problem-solving approach to implement change and would benefit from targeted support.

As part of the health and wellbeing coach's induction, training for the role was provided by Enable[8] which covered health coaching and motivational interviewing. The on-site Chronic Pain Self-Management team (CPSMT) provided training which focussed on developing knowledge around chronic pain and chronic pain self-management skills as well as existing care pathways within the Chronic Pain Service.

The health and wellbeing coach aimed to offer patients up to six sessions. However, patients could attend fewer or more sessions. This decision was based on a discussion with the patient about their needs. Sessions were offered Monday-Friday, between 9am-5pm.

2.5.2. Social prescriber at Epsom and St Helier University Hospitals NHS Trust

A social prescriber was appointed to work within the pain clinic at Epsom and St Helier Hospital. The role was created to support people living with chronic pain by providing holistic solutions for patients. The main purpose of this role was to help patients self-identify existing and potential issues, connect them to local support services, and aid them in reaching their self-identified health and wellbeing goals. This occurred in one-to-one appointments which were conducted either remotely or in person.

Patient referrals to the social prescriber were made by the Trust's chronic pain team, guided by criteria such as a patient appearing willing to engage and not currently experiencing an acute issue. Patients could receive reading materials, such as leaflets and posters, with information on the role of the social prescriber. As this pilot was commissioned by Southwest London ICB, for a patient to be eligible for referral to the social prescriber, they had to live or be registered to a GP in Southwest London.

As part of the induction to the role, mandatory training was provided by Merton Connected[9] . Additional

[8] Enable (enablelc.org)
[9] Merton Connected, Volunteering, Charity Organisations, Social Prescribing.

training was also provided by the onsite pain clinic.

The social prescriber aimed to offer patients up to six sessions. However, patients could attend fewer or more sessions, as appropriate. Sessions were offered Monday-Friday between 9am-5pm.

3. Evaluation Approach

3.1. Purpose and scope

The purpose of the evaluation was to understand the benefits of and ways to improve the link worker role within pain clinics with the view to scaling up across Southwest London. The evaluation focused on the two pilot sites at St George's and Epsom and St Helier pain clinics.

This evaluation focused on the link worker in pain clinics pilot (May 2022 – August 2023). The St George's health and wellbeing coach was appointed in May 2022, completing a 12-month-fixed-term contract. Due to delays around recruitment, the Epsom and St Helier social prescriber was appointed in August 2022. They also completed a 12-month-fixed term contract. The intention of the evaluation was not to directly compare the two link worker roles, but instead to understand how each role and this model of care can be best supported in a secondary care setting.

The evaluation aimed to address the following questions:

1. What is the acceptability of the model for patients (including experience and satisfaction)?
2. What are the benefits for patients?
3. What is the acceptability and feasibility of the model for professionals in pain clinics?
4. What are the benefits for healthcare providers?
5. What are lessons for implementing and delivering the model to support improvements and spread and adoption?

3.2 Design

This was a prospective service evaluation using a mixed methods approach of quantitative and qualitative data collection (Table 1: Summary of data collection methods). The service evaluation used:

- Service/clinical data collected by the pain clinic staff and link workers.
- Data collected from link workers and clinical staff via focus groups and interviews.
- Data collected from patients via an anonymous satisfaction survey and interviews.

Table 1: Summary of data collection methods

Collection method	Description	Analysis
Service / clinical data	Link workers used an Excel spreadsheet to collect data on patient demographics, reason for referral, and pain history. Two outcome measures MyCaw® and PSEQ score (see below) were collected at baseline and post-intervention, as appropriate.	Any patient identifiable information was removed from the spreadsheet before being sent to the HIN. Patient postcode data was removed and replaced with the calculated Interval of Multiple of

		Deprivation score (range 1-10). Data was analysed in Excel using descriptive statistics.
Interviews and focus groups	Link workers were invited to complete individual interviews and clinical staff were invited to complete a focus group. Patients were recruited via the link workers and completed individual interviews. Topic guides for each group are provided in Appendix A, B, and C.	Interviews and focus groups were recorded and transcribed. Themes were coded in Excel using a deductive approach based on the evaluation objectives.
Anonymous online patient satisfaction survey	All patients were asked to complete an anonymous patient survey, either via paper or online format. This explored satisfaction with the organisation, content, and treatment in sessions. The survey is presented in Appendix D.	Responses to the patient satisfaction survey were exported to an Excel spreadsheet and analysed using descriptive statistics.

Key: PSEQ = Pain Self Efficacy Questionnaire, MyCaw® = Measure Yourself Concerns and Wellbeing

3.2.1.1. Measure Yourself Concerns and Wellbeing (MyCaw®) measure

MyCaw® is an individualised questionnaire, designed to evaluate holistic and personalised approaches to supporting people. The link worker completed a MyCaw® with patients at baseline and post-intervention. The patient could document up to two concerns that they would most like help with and rank them from 0 = 'not bothering me at all', to 6 = 'bothers me greatly' (Appendix E). The MyCaw® worksheet included a question about wellbeing. The wellbeing component was ranked from 0 = wellbeing is 'as good as it can be', to 6 =wellbeing is 'as bad as it can be' (Appendix E).

3.2.1.2. Pain Self-Efficacy Questionnaire (PSEQ)

The PSEQ is a 10-item questionnaire which assesses the confidence of people with any type of chronic pain in managing their pain and its impact. It covers enjoying activities, household daily activities, social life, coping in general, work, leisure activities, coping with pain without medication, accomplishing goals, living a normal lifestyle, and becoming more active, all 'despite pain'. Each component is rated from 0= 'not at all confident' to 6= 'completely confident'. The total score, ranging from 0 to 60, is calculated by adding the scores for each item. Higher scores reflect stronger self-efficacy beliefs (Appendix F).

4. Findings

Quantitative and qualitative data were collected and analysed. Table 2: Sample size for quantitative and qualitative data by presents the sample size for data collected at each site. Findings for the first four evaluation questions are presented by site. Findings for the last evaluation question are presented by theme, using combined results from both sites.

Table 2: Sample size for quantitative and qualitative data by pilot site

St George's University Hospital NHS Foundation Trust	Epsom and St Helier University Hospital NHS Trust
Quantitative data	**Quantitative data**
• 30 patients	• 44 patients
Qualitative data	**Qualitative data**
• 1 x health and wellbeing coach	• 1 x social prescriber
Clinical staff: • 1 x consultant clinical psychologist • 1 x clinical nurse specialist • 2 x physiotherapists	Clinical staff: • 1 x psychologist / clinical Lead • 1 x consultant in anaesthetics and pain medicine • 1 x physiotherapist
• 4 x patients	• 4 x patients
Anonymous Patient Satisfaction survey	
• 18 patients overall	

4.1. Overview of patient populations

4.1.1 St George's University Hospitals NHS Foundation Trust

4.1.1.1. Demographic characteristics of patients

The health and wellbeing coach had a total of 30 patient referrals. All 30 (100%) patients accepted their referral. Demographic characteristics of patients who accepted a referral to the health and wellbeing coach can be found in Table 3:Demographic breakdown of patients. Patients were largely female and aged 18-64 years old, from a mix of ethnic groups. Although postcode data was collected for all patients to calculate Intervals of Multiple Deprivation (IMD), the number of patients in each quintile were too small to be presented in this report, as this would compromise the anonymity of patients. However, there appeared to be an even spread across levels of deprivation. Patients engaged with the health and wellbeing coach between July 2022 and March 2023, and were registered to GP practices in four boroughs: Croydon, Merton, Sutton and Wandsworth.

Table 3:Demographic breakdown of patients accepting a referral to the health and wellbeing coach

Characteristic	Number	%
Sex		
Male	4	13
Female	26	87
Ethnicity		
Asian / Asian British or Black /	9	30

Black British		
White (including white other)	11	37
Other and Mixed	10	33
Age group		
18-64	23	77
65+	7	23
Employment		
Working or training	10	33
Not working due to pain	10	33
Retired or not working due to other reasons	10	33

4.1.1.2. Pain experienced by patients

Most patients (N=11, 36.7%) had pain in the lumbar area (low back, hip, buttock). Ten (33.3%) patients had widespread pain (more than 3 areas). The remaining nine patients had pain either in their lower limbs (N=5), in their head face and mouth (N=3), or abdomen / pelvis (N=1). Duration of pain ranged from 1-15+ years. Most patients (N=14, 47%) had been in pain for 15 or more years, followed by 10 patients (33%) being in pain for 5-15 years, and six patients (20%) in pain for 1-5 years.

4.1.1.3. Patient referrals to the health and wellbeing coach

Patients were referred to the health and wellbeing coach via several pathways. Most patients (N=14, 47%), were referred from the clinics (MDT assessment clinic or CNS follow-up clinic) or following completion of a Pain Management Programme (N=12, 40%). Four (13% were referred from 'other' sources (including pain clinic). Reasons for referral to the health and wellbeing coach were varied (Table 4: Reason for referral to health and wellbeing coach), with the most common reason being for further support with implementing relaxation strategies.

Table 4: Reason for referral to health and wellbeing coach

Referral reason	Number
Relaxation	13
Engaging with activities	11
Improving movement	7
Dietary changes	6
Better sleep	3
Structure and routine	3

*Note: numbers do not add up to 30 as two referral reasons could be given for each patient.

4.1.1.4. Sessions

There was an even split of patients receiving the sessions in-person (N=15) compared to virtually or by telephone (N=15). The number of sessions booked ranged from 1-14, with a median of 3 and an interquartile range (IQR) of 5. Number of sessions attended ranged from 0-14 with a median of 2 and IQR of 5. Out of a total of 122 sessions booked, 112 (92%) were attended. Nine patients did not attend (DNA) one or more booked appointments. Out of the nine patients, three had booked their first appointment but failed to attend any. The health and wellbeing coach attempted contact with these three patients but received no response.

4.1.2 Epsom and St Helier University Hospital NHS Trust

The social prescriber received a total of 64 patient referrals of which 44 (68.8%) were accepted. The reason for most patients not accepting the referral was due to the social prescriber being unable to contact the patient to book an appointment (N=8, 40%). Another seven (35%) patients directly declined the referral with documented reasons including that the patients' needs were out of link workers' scope of practice e.g., medication review. Five patients (25%) had 'other' reasons for non-acceptance which mostly related to being out of borough so not eligible for the service due to funding.

4.1.2.1. Demographic characteristics of patients

Table 5: Demographic breakdown of patients accepting a referral to the social prescriber outlines the demographic characteristics of patients who accepted a referral. Most patients were female, aged 18-64 years old and white. Although the postcode was collected for all patients to calculate IMD, the number of patients in each quintile was too small to be presented in this report, to protect anonymity of patients. However, there was a relatively even spread across levels of deprivation. All patients accepting the referral were registered to GP practices included in the required Southwest London boroughs (Croydon, Kingston, Merton, and Sutton). Patients engaged with the social prescriber between October 2022 and August 2023.

Table 5: Demographic breakdown of patients accepting a referral to the social prescriber

Characteristic	Number	%
Sex		
Male	11	25
Female	33	75
Ethnicity		
Black / Asian or Minority Ethnic Group (including 'other')	12	29
White (including white other)	30	71
Age group		
18-64	33	75
65+	11	25
Employment		
Working or training	9	22
Not working due to pain	10	24
Retired or not working due to other reasons	22	54

*Note: where the number does not add up to 44, this is due to missing or unknown data.

4.1.2.2. Patient experience of pain

Most patients (N=24, 56%) had widespread pain (more than 3 areas). Five (11%) had pain in their lumbar, lower back, hip and buttock. Three patients (7%) had pain in their thoracic, upper back, chest, and another three (7%) in their head, face, and mouth. Two patients had pain in each of the following sites: abdominopelvic (5%), cervical / neck (5%), and lower limbs (5%). For two patients (5%), pain site was unknown. Of those patients with pain duration documented, nine (27%) had been in pain for 15 years or longer, seven (21%) for 5-15 years, and 17 (52%) for 1-5 years.

4.1.2.3. Referrals

Patients were referred to the social prescriber via several pathways. The most common referral source was ward (including MDT assessment / clinic) (N=29, 66%), followed by post-pain-management-programme (N=13, 30%), and 'other' (including pain clinic) (N=2, 1%). Reasons for referral to the social

prescriber were varied, though the most common were for social support (Table 6: Reason for referral to social prescriber).

Table 6: Reason for referral to social prescriber

Referral reason	Number
Social support	21
Isolation	19
Improvement movement / exercise	10
Financial	8
Mental health	4

*Note: numbers do not add up to 44 as two referral reasons could be given for each patient.

4.1.2.4. Sessions

The majority (N=38, 86%) of sessions were completed virtually or by telephone with a small proportion of sessions (N=6, 14%) completed in person. Number of sessions booked ranged from 0-7, with a median of 1 and IQR of 1.25. Number of sessions attended ranged from 0-7 with a median of 1 and IQR of 1. Out of a total of 87 sessions booked, 80 (92%) were attended. Five patients (11%) did not book or attend any appointments. Reasons for not booking appointments after accepting a referral to the social prescriber included receiving advice or signposting via email instead of in a session, or due to the patient being too unwell. Six patients (14%) did not attend one or more of their booked appointments. Reasons for non-attendance included being abroad or experiencing a bereavement.

4.2. Acceptability of the model for patients

4.2.1. St George's University Hospitals NHS Foundation Trust

The health and wellbeing coach, alongside staff interviewed, shared the perception that they felt patients were satisfied overall with their experience. All patients interviewed at the St George's Hospital pain clinic reported that they were satisfied with their engagement with the health and wellbeing coach, finding it a positive experience. Patients appreciated the opportunity to 'talk about things they were going through', commenting that the health and wellbeing coach was 'kind' and 'a good listener'. These attributes alongside reports of their open-mindedness and non-judgemental attitude, meant that their role was well received:

> *"They didn't judge me or question me. They just reenforced the positive changes I had made" – Patient (St George's)*

During interviews, patients reported 'getting a lot' from the experience, with one describing their time with the health and wellbeing coach as 'life changing'. Patients commended the health and wellbeing coach's ability to help them set and progress towards their goals:

> *"For once, I feel like I have control of my life" – Patient (St George's)*

4.2.2. Epsom and St Helier University Hospital NHS Trust

The social prescriber described 'holding a space' for patients, providing emotional and practical

support, which often extended beyond the scope of what was typically expected from this role. Patients interviewed discussed how their referral to the social prescriber 'came at the right time'. They spoke positively about the social prescriber, describing them as 'empathetic' and 'helpful'. They appreciated being able to speak to someone about different topics:

> *"They (the social prescriber) were a lifeline – a real saviour. Almost like a cushion, providing that safe space." – Patient (Epsom and St Helier)*

4.2.3. Patient Satisfaction Survey

Out of the 74 patients who accepted a referral in the pilot, 18 (24%) completed a satisfaction survey. Responses to questions indicate a high level of satisfaction with the service, including the information received, how they were treated, and the ability of the link workers to address concerns. No one reported dissatisfaction with any element of the model of care (Table 7: Responses to patient satisfaction survey.

Table 7: Responses to patient satisfaction survey

Survey question	Number	%
How satisfied were you with information you received before first session?		
Extremely satisfied	13	72
Mostly satisfied	4	22
Neither satisfied nor dissatisfied	1	6
How satisfied were you with the sessions?		
Extremely satisfied	14	78
Mostly satisfied	4	22
How satisfied were you that the professional delivery the sessions had the skills to help address concerns?		
Extremely satisfied	16	89
Mostly satisfied	2	11
How satisfied were you with how you were treated?		
Extremely satisfied	16	89
Mostly satisfied	2	11
How was your overall experience of the service?		
Extremely positive	15	83
Mostly positive	3	17

Note: Where the following responses: 'neither satisfied nor dissatisfied', 'mostly dissatisfied' or 'extremely dissatisfied' are not reported, this option was not chosen by the patient.

Table 8: Strategies used in sessions with link workers that patients found helpful outlines the strategies used by link workers that patients found most helpful, with goal setting plans being the most popular.

Table 8: Strategies used in sessions with link workers that patients found helpful

Strategies used	Number
Goal setting plans	15
Signposting to additional organisations	6
Diaries / journals	5
Homework	5

Links to websites / podcasts	5
Schedules / timetables	3
Suggestions for further reading	3
Information sheets	3

*Note that the number does not add up to 18 as 16 patients answered this question and could pick multiple options.

Patients were provided with the option of providing additional comments in the survey. Eleven of the patients further emphasised their satisfaction with the service, with three patients highlighting that they would have liked the sessions to continue.

4.3. Benefits to patients

4.3.1. St George's University Hospitals NHS Foundation Trust

4.3.1.1. Quantitative outcome measures

In their first session, patients were asked to document up to two MyCaw® concerns. The most common was related to mental and emotional health (Table 9: List of concerns documented on the MyCaw®).

Table 9: List of concerns documented on the MyCaw® worksheet (St George's site).

MyCaw® concerns	Number
Mental and emotional concerns	9
Physical concerns	7
Practical concerns	7
Wellbeing concerns	4

*Note: concerns include 1st and 2nd documented concern at baseline, collected from 20 patients. Therefore, total concerns do not equal total number of patients.

A MyCaw® was completed with 20 (67%) patients at baseline. Thirteen (65%) of these 20 patients completed a MyCaw® for their first concern post-intervention. Twelve patients recorded a reduction in their concern, with one patient recording the same level of concern due to experiencing increased pain. The average level of concern decreased from 5.54 (SD=0.97) at baseline to 2.77 (SD=1.69) post-intervention.

Seven patients ranked a second MyCaw® concern at baseline and post-intervention. All these patients reported a decrease in level of concern, with the average declining from 5 (SD=1.29) at baseline to 2.29 (SD=0.95) post-intervention.

Thirteen patients ranked their wellbeing at baseline and post-intervention. All patients reported an improvement in wellbeing apart from one patient who reported the same score due to experiencing worsened pain. The average score for wellbeing decreased from 3.92 (SD=1.32) at baseline to 2.77 (SD=1.54) post-intervention, representing an improvement.

The same thirteen patients completed a PSEQ at baseline and post-intervention. Eleven patients reported an increase in self-efficacy, one reported the same score, and another reported less self-efficacy. Reasons for these scores are unknown. The average PSEQ score for self-efficacy increased from 30.77 (SD=15.35) at baseline and 35.77(SD=14.67) post-intervention.

4.3.1.2. Qualitative findings on benefits

The health and wellbeing coach reported that, through their sessions, patients felt like they could

rediscover interests and skills which provided a distraction from persistent pain. One of the most common benefits reported by the health and wellbeing coach was around mental health and wellbeing. They also described patients feeling more confident to 'achieve things they didn't think were possible', such as socialising, going to the gym, and changing diet. Positive changes to one aspect of a patient's life contributed to a 'spillover effect', with reports of patients stating, 'If I can do that, then I can do other things!". This impact was also recognised by staff working alongside the health and wellbeing coach, who highlighted a positive change in patients' outlook:

> *"They often don't think they can make changes, but with their (health and wellbeing coach), they can." – Staff member (St George's)*

Patient reported benefits included a reduction in feelings of anxiety, change in behaviour, and a change in mindset. Sessions offered an opportunity to explore topics patients would not always feel comfortable speaking to family or friends about. They felt empowered to apply new approaches in their daily life, and pursue activities that positively impacted their mental and physical wellbeing:

> *"I now go swimming a couple of times a week….it has made me feel a lot happier about life." – Patient (St George's)*

The health and wellbeing coach also helped patients celebrate progress, no matter how small, and coached them to stop putting pressure on themselves to get it right all the time:

> *"Now I can look at things that really used to overwhelm me and they don't anymore. I've laid a lot of ghosts to rest." – Patient (St George's)*

4.3.2. Epsom and St Helier University Hospital NHS Trust

4.3.2.1. Quantitative outcome measures

The most common MyCaw® concern documented in the first session related to wellbeing (Table 10: List of concerns documented on the MyCaw® worksheet (Epsom and St Helier site).

Table 10: List of concerns documented on the MyCaw® worksheet (Epsom and St Helier site).

MyCaw® concerns	Number
Concerns about wellbeing	8
Practical concerns	1
Physical concerns	1
Mental and emotional concerns	1

*Note: concerns include 1st and 2nd concern at baseline – collected from 6 patients. Therefore, total concerns do not equal total number of patients.

Three patients completed a MyCaw® for their first concern at baseline and post-intervention. One patient reported a reduction, and two reported the same level of concern, attributed to factors outside the context of this model of care. For these patients, the average level of concern decreased from 5 (SD=1) at baseline to 4.7 (SD=1.2) post-intervention. Only one patient ranked a second MyCaw®

concern at baseline and post-intervention. Therefore, no analysis was completed for the second concern.

Four patients ranked their wellbeing at baseline and post-intervention. Two patients reported improved wellbeing and two patients reported the same level of wellbeing between the two timepoints. The average score for wellbeing at baseline amongst these patients improved from 4.75 (SD=0.5) at baseline and 3.75 (SD=1.9) post-intervention.

Four patients completed a PSEQ at baseline and post-intervention. Three patients reported increased self-efficacy and one patient reported decreased self-efficacy. This was the same patient who experienced negative personal circumstances. The average score for self-efficacy increased from 32 (SD=10.1) at baseline to 35.5 (SD=13.1) post-intervention.

4.3.2.2. Qualitative findings on benefits

The social prescriber described one key patient benefit as providing access to emotional support. Patients shared that they appreciated the 'space to talk' and 'not feel judged'. They also felt their role helped to improve patient's self-efficacy. The clinical team highlighted how the social prescriber role provided invaluable links with the community and wider local services, as well as the offer of social support, for example, in relation to housing and benefits.

Patients described experiencing positive changes in their behaviour and mindset. Two patients explained how the social prescriber helped them access bereavement counselling. One patient reported an increase in physical and social activity, through joining a walking club. Another patient shared that their sessions with the social prescriber had contributed to them avoiding 'going into that dark place' and helping them 'let go of things'. Patients said this was achieved by the social prescriber supporting them to take 'baby steps' towards a set goal. Without the support of the social prescriber, the patient felt that they would have been in a worse place:

> *"If I didn't have (the social prescriber), I don't want to think where I would be." – Patient (Epsom and St Helier)*

4.4. Acceptability and feasibility of the model for professionals

4.4.1. St George's University Hospitals NHS Foundation Trust

Pain Service staff highlighted that although the role of health and wellbeing coach did not reduce their own workload, it added to the portfolio of support the team could offer. They commented that they felt is was helpful to be able to offer patients an additional intervention which otherwise would not have been available, for example, where a patient may have completed a Pain management Programme but would benefit from additional support around particular goals. However, staff interviewed emphasised that the role of a health and wellbeing coach was an adjunct that provided valuable additional support, but did not replace the support offer by existing clinical roles, such as psychologists, and physiotherapists:

> *"(I) had some reservations that health and wellbeing coaching may be seen as an answer to staffing issues we have here or complex issues we see here." Staff member (St*

George's)

The health and wellbeing coach felt well supported to deliver their role and received via regular supervision. However, the clinical team providing support were not allocated additional time or resource to fulfil training and development duties the link worker role required. Despite the positive impact of the health and wellbeing coach, it was recognised that the recruitment, induction, and ongoing support further stretched their already limited time and capacity. For the health and wellbeing coach, a barrier to delivering the sessions was lack of available confidential space to talk with patients. This negatively impacted on the health and wellbeing coach who felt restricted in what they could offer patients as they were unable to consistently schedule in sessions.

4.4.2. Epsom and St Helier University Hospital NHS Trust

Pain clinic staff described how the social prescriber provided them with another option for onward referral for further support when they were unable and/or it was inappropriate to continue to see a patient:

> *"For us it's been another option which has been really valuable in terms of referrals that have come back through who don't necessarily need us again, but actually they need a bit more support." – Staff member (Epsom and St Helier)*

One limitation of the role reported by the social prescriber was the reliance on the services and organisations available to the patient in their local area. To successfully signpost or refer to a service, patients typically had to live, work or be registered with a GP in that area. There were occasions when patients could not be referred to appropriate support services because none were available in their area. In such circumstances, the social prescriber focused on offering support themselves. A consequence of this was that they did not feel entirely clear about the remit of their role.

The social prescriber reflected on the solitary nature of the role. They discussed how placing this role in the community rather than a hospital-based service may help them to feel more connected with other link workers and increase information sharing, to provide better support to patients. Staff at Epsom and St Helier shared this opinion and reported that the link worker role might work better being part of Southwest London network within the community. They also suggested that this might provide more value for money from them role because it could support more referral from across different providers and pathways.

4.5. Benefits for healthcare providers

4.5.1. St George's University Hospitals NHS Foundation Trust

Patients interviewed did not report a change in their interaction with healthcare services, such as a reduction in GP or A&E attendance. One patient reported a continued need to attend other healthcare appointments to help manage pain and due to concern about other symptoms being related to their chronic pain. Despite this, the health and wellbeing coach felt that because of their involvement patients were better equipped to get 'more' out of other healthcare related appointments they attended, taking a more proactive and engaged approach to their care. This extended to feeling empowered to

advocate for themselves and be clearer in their communication. It was thought that this could positively impact healthcare providers:

> *"Because of the way they're thinking differently with me, they're applying that to other sessions, and I think that helps the other health professionals as well." – Link worker (St George's)*

Clinical staff reported that they did not perceive any difference in healthcare utilisation for patients accessing support from the link worker. They highlighted that this role would be unlikely to impact meaningfully on patients utilisation of healthcare, such as reducing A&E attendance due to their chronic pain.

4.5.2. Epsom and St Helier University Hospital NHS Trust

Patients interviewed did not report a change in their utilisation of healthcare services, such as a reduction in GP or A&E attendance. However, the social prescriber discussed their sessions potentially leading to 'expanded horizons' for patients, with increased interactions with relevant organisations. They highlighted that it was difficult to determine if there had been any benefits to healthcare providers without long-term following up with patients. The clinical team speculated that it was ambitious to expect the social prescriber to have a direct effect on A&E attendance.

4.6. Lessons for implementing the link worker model to support improvements and spread and adoption

There were common themes across both pilot sites about the lessons for implementing the link worker model of care to support improvement and spread and adoption.

4.6.1.1. Role of the link worker

Neither link workers had previous experience working with people living with chronic pain and/or pain services. The key focus was to provide holistic, individualised support, 'treating the person, not the condition'. However, link workers were supported by clinical teams to help develop their knowledge around pain, which was deemed important. Reflecting on the 'lower-than-expected' referral rates, the idea of having a combined link worker able to fulfil health and wellbeing coach as well as social prescriber duties was raised by staff at both sites. Recruiting someone with skills and experience in these areas was deemed as desirable by clinical staff and realistic by the link workers. It was observed that social prescribing could be limited in what it could offer. Whereas being able to offer coaching in addition to patients was thought to be a better use of the link worker role and potentially increase referrals. Both teams spoke about some situations with patients where it would have been more suitable for the other role to provide the best support. The potential for the link worker role to extend to other conditions was also considered. This idea had been trialled to some degree at St George's where the offer was extended to patients with sickle cell disease. However, one staff member highlighted that extending the role to other conditions should be considered carefully, to ensure a team were 'ready' for this model of care and understood its use and value.

4.6.1.2. Referrals to link workers

This model of care received a lower number of referrals than initially expected across both sites. Lower than anticipated referral rates resulted in link workers having increased capacity and to be more flexible in their approach to sessions. This was regarded as a benefit by link workers, especially when working with patients who presented with complex need. In addition, link workers were able to contribute to other activities, such as joining sessions on the Pain Management Programme and establishing links with healthcare professionals. An example of conducting joint working with a trainee clinical psychologist was given. These opportunities were perceived as providing shared learning and peer support.

Staff members commented on the difference between delivering this model of care in a secondary care setting as opposed to within primary care. One major difference highlighted was the patient 'footfall' being significantly higher in primary care. Additionally, it was observed that patients referred to the link workers in secondary care appeared to have more co-morbidities and complex need which could contribute to them requiring more sessions. Staff discussed the importance of identifying suitable referrals, preparing a patient for a referral to the link worker, providing key information, and not simply 'sending them' with little detail.

4.6.1.3. Sessions with the link worker

For the health and wellbeing coach, the clinical team shared the view that six sessions were an appropriate number because they felt that at least four sessions are typically required to make a change. Five (17%) patients attended more than six sessions, suggesting that a level of flexibility should be applied. The health and wellbeing coach also described patients often wanting a few weeks in between each session to allow time to make changes. In contrast, clinical staff at Epsom and St Helier stated that the most appropriate number of sessions delivered by the social prescriber would be three, with six sessions being considered too many. The reason for this was that they felt by the third session patients would be expected to have been successfully linked in with services available in their local community.

4.6.1.4. Funding and resource allocation to support sustainability and scale-up

Several key improvements were highlighted relating to infrastructure and resourcing that would support the sustainability and scale-up of the link worker model.

Staff reported that there were no additional funding and capacity were allocated to pain clinic staff to develop, implement, and support delivery of the link worker role. It was the responsibility of the team at each site to navigate governance, induct the link worker, allocate clinical space for sessions, set-up IT systems, undertake regular supervision and support any associated training and development needed. Key staff at both sites were required to attend pilot project meetings and undertake work relating to the actions coming out of meetings to support the pilots. Balanced against delivering business as usual activities within the pain clinic was felt to be 'quite demanding' at times. Staff recognised that their own passion and enthusiasm for the new model was a driving force for the successful delivery of the pilot. Although they valued the input of the link worker role, they acknowledged finite resources might mean that this post may not be regarded as such a high priority compared to other roles required in a secondary care setting.

At the Epsom and St Helier, there were challenges due to commissioning arrangements for the pain clinic. The Trust is funded by two ICBs to provide care for patients. However, only patients with a GP or home address in Southwest London were eligible, which they felt provided an operational challenge to the service and an inequality in access to care for patient. Staff highlighted the importance of finding an approach to joint commission the model with the two ICBs or get agreement from the Trust to establish the post funded within local budgets.

5. Conclusions

A total of 74 patients accepted a referral for a link worker. Patients expressed a high level of satisfaction with the care provided by the link workers and reported direct benefits in their quality of life. Quantitative outcome measures indicate improvement in individual's mental, emotional, and physical health and wellbeing. Overall wellbeing improved in addition to. Participants also described increased feelings of self-efficacy, a positive change in their behaviour and outlook on life.

Staff also regarded the model as acceptable and feasible within a pain clinic setting. Staff were positive about the work of link workers and felt that they added value to the team. The added benefit of offering the link worker model of care for patients requiring further support was welcome. However, staff stressed that this role did not reduce their own workload but instead added to it due to requirements to deliver activities such as inductions and supervision. They also highlighted that this role should not be recruited to replace other posts such as a nurse, psychologist, or physiotherapist.

It was not possible to use quantitative measures to determine any impacts on healthcare providers due to the 12-month duration of the pilot and restrictions surrounding data linkage. Qualitative data suggests that there was no change in healthcare service use, such as reduced A&E attendance. However, staff highlighted that expecting a reduction in healthcare service use was ambitious as this is influenced by multiple factors. A potential benefit to healthcare providers might be that patients feel better equipped to 'get the most' out of other healthcare appointments due to increased ability to communicate and advocate for their care.

There were several lessons learnt for implementing the link worker model of care to support improvements and spread and adoption. Referrals to the link workers were lower than initially anticipated. Referral rates were based on expected 'footfall' within a primary care setting. It was observed that patients referred to the link workers in secondary care appeared to have more co-morbidities and complex need which could contribute to them requiring more sessions and therefore resource. Reflecting on the 'lower-than-expected' referral rates, the idea of having a combined link worker able to fulfil health and wellbeing coach as well as social prescriber duties was raised by staff at both sites. Both teams spoke about some situations with patients where it would have been more suitable for the other role to provide the best support. The potential for the link worker role to extend to other conditions was also considered.

Staff recognised that their own passion and enthusiasm for the new model was a driving force for the successful delivery of the pilot. Although they valued the input of the link worker role, they acknowledged finite resources might mean that this post may not be regarded as such a high priority compared to other roles required in a secondary care setting. At Epsom and St Helier, there were challenges due to commissioning arrangements for the pain clinic. Staff highlighted the importance of finding an approach to joint commission the model to ensure patients were eligible for the model of care, regardless of postcode.

6. Limitations

This evaluation successfully collected quantitative data on 74 patients across the two sites. The evaluation collected qualitative insights from two link workers, seven members of staff, and eight patients. However, there were some limitations:

6.1. Quantitative data

- Lower than anticipated referral rates resulted in a small patient sample size. This meant that subgroup analysis was not possible.
- It was not always possible to complete the outcome measures with patients at baseline and post-intervention due to a proportion of patients only completing one session with the link worker.
- It was not possible to collect quantitative data related to observing the impact of the model of care on healthcare providers. This was due to restrictions in patient data linkage, in addition to time restrictions of the pilot not leaving enough time to observe longer-term impacts.

6.2. Qualitative data

- The sample size of interview and focus groups was small; however, that is reflected in the low number of staff and patients involved in the pilot.
- Patients who completed an interview may be subject to selection and/or response bias.
- It was not possible to collected perceptions from patients who did not accept a referral or failed to attend appointments.

6.3. Survey data

- Despite the questionnaire being anonymous, patients completing the questionnaire may be subject to selection and response bias. A large proportion of patients did not complete a survey.
- The overall sample was too small to differentiate satisfaction between the two pilot sites.

6.4. Lack of comparison / counterfactual

- Although the link worker in pain clinics model appears to have been well received, there is no direct comparison in a different setting.

7. Recommendations

The evaluation makes the following recommendations based on quantitative and qualitative findings. Recommendations provided are intended to support improvements and spread and adoption:

7.1. Supporting link worker to deliver sessions

- Pain clinic services need to ensure that the link worker is well supported to deliver their sessions. For example, providing a confidential space to conduct sessions with patients.
- The link worker should be embedded in specialist teams that are able to provide support and supervision, in addition to providing opportunities for professional development.
- Support should be provided to the link worker to further develop knowledge in long term conditions and experience working within a secondary care NHS setting.

7.2. Extending the scope of the link worker role

- Pain clinics should consider recruiting a link worker with existing skills and experience in both health and wellbeing coaching and social prescribing. This will help to broaden the scope of practice and have the potential to increase referrals and rates of uptake by patients.
- Trusts could consider employing link workers across several specialities or conditions. This may help to increase referral rates and ensure that the role of the link worker is best utilised.

7.3. Considerations for future commissioning

- Future commissioning should factor in cost and capacity associated with additional tasks required to be carried out by clinical teams hosting link workers such as providing induction and training alongside regular supervision.
- Future commissioning should be aware of and account for restrictions faced by Trusts that are funded by more than one ICB to increase patient accessibility of the link worker model of care in this setting.
- Alternatively, funding solutions should consider employing the link worker through the Trust they are working for. This may overcome the barrier of only a proportion of patients being eligible for the intervention and simplify governance requirements for this role.

7.4. Further research

- Future research could examine the impact of this model of care on healthcare service use, such as GP and A&E attendance. This could be achieved through quantitative data linkage processes to track a patient over a longer period. However, it must be noted that this is likely influenced by complex factors. A more suitable metric may be medication compliance, secondary care service referrals, or a patient's perceived ability to manage their condition.
- Future pilots should focus on increasing referral rates and therefore patient sample size. This would facilitate additional subgroup analysis and provide greater insights on which patient groups are benefiting the most and those experiencing health inequalities.
- To increase the response rate to the question around patient satisfaction, the satisfaction survey could be replaced with single 'friends and family' test question i.e., 'Would you recommend to a friend?'.

8. Appendices

A) Topic guide for interview with link worker

Pre interview procedures

- Thank you for agreeing to participate in this interview.
- This interview is part of the Link Workers in Pain Clinic Evaluation which is being conducted by the Health Innovation Network**.** The evaluation aims to understand the benefits of and ways to improve the link workers role within pain clinics with the view to scaling up across Southwest London.
- My name is Kate, I work at the Health Innovation Network and I will be completing this interview with you today.
- Before we start, do you have any questions?

Introduction:

- Our interview today will be focusing on your experience of the link workers in pain clinic pilot. It will last up to 1 hour.
- There are no right or wrong answers to questions in this interview.
- Everything you say is completely confidential and will be made anonymous.
- However, it is important to highlight that if discussions raise any safeguarding issues, I will be required to contact the appropriate authorities.
- The more honest you can be in your answers the more it will contribute to the project.
- [Where applicable] We may have worked together on this project previously, but if you can answer the questions as if we're meeting for the first time that would be really helpful
- As a reminder we will be recording this interview.

START RECORDING

So for the recording, can you please introduce yourself and confirm whether you are happy to begin the interview and to be recorded.

1. **I would like to start by exploring the link worker in pain clinics model and your involvement.**

1A. Please can you talk me through your role?

Prompt:

- *What is your role? Aims / Objectives? Purpose , duties?*
- *How does it work in this setting? E.g., compared to PCN?*

1B. Can you describe the type of support you offer patients in your role?

Prompts:

- What is within scope of the sessions / your support?
- How is support structured e.g., is this influenced by MyCaw?

2. **We are now going to move onto discussion about the implementation of your role**

2A. What supported you to be able to carry out your role and support implementation of the model of care / intervention?

Prompts:

- Team
- Environment
- Preparation / training

2B. What challenges have you experienced in this pilot?

Prompts:

- Referrals? (low referral rates + appropriateness)
- Training & Support + Supervision
- Resources e.g., community links, information
- Environment: e.g., confidential space
- How might the challenges differ to carrying out this role in a PCN?

2B. What has or would help facilitate / mitigate the challenges described in your role?

Prompts:

- Flexible working arrangements
- Extension to other specialities

3. **Now I am going to ask you to reflect on the impact of your role and the intervention on patients.**

3A. Please can you talk to me about how your role / the sessions this model of care, benefit patients?

Prompts:

- *Wellbeing? Physically / Emotionally?*
- *Ability to self-manage*
- *Clinical outcomes?*
- *Linking up with community assets*
- *Any other benefits for patients?*
-

3B. Please can you talk to me about which ways your role / the sessions / this model of care, benefit health care providers?

Prompts:

- *Alleviation of burden on services?*
- *Evidence of changes to e.g., re-referral rates, GP, ED?*
- *Linking up with community assets (e.g., better links between primary , secondary and voluntary care). Has the link worker aided better communication / links between services?*
- *Shared learning?*
- *Any other benefits for health providers?*
-

4. **Finally I am now going to ask about sustainability.**

4A. What are the lessons learnt for implementing and delivering this model of care in the future (link workers in pain clinics and / or other settings)?

Prompts:

- *Eligibility criteria?*
- *What worked well / not so well?*
- *Where and what improvements could be made?*
-

4B. What would support spread and adoption of this model of care?

Prompt:

- E.g., Capacity, Infrastructure, Flexibility in approach

-

Closing the focus group

That's all of the discussion points I wanted to cover.

Is there anything else that you would like to ask or any other comments that you would like to make before we finish the focus group?

Thank you for your time.

B) Topic guide for focus group with staff

Pre focus group procedures

- Thank you for agreeing to participate in this focus group.
- This focus group is part of the Link Workers in Pain Clinic Evaluation which is being conducted by the Health Innovation Network**.** The evaluation aims to understand the benefits of and ways to improve the link workers role within pain clinics with the view to scaling up across Southwest London.
- My name is Kate, I work at the Health Innovation Network and I will be running this focus group today.
- Before we start, do you have any questions ?

Introduction:

- Our focus group today will be focusing on your experience of the link workers in pain clinic pilot. It will last up to 1 hour.
- There are no right or wrong answers to questions in this focus group.
- Everything you say is completely confidential and will be made anonymous in the reporting.
- I ask that we make an agreement within the group that what we share within the group stays in the group.
- However, it is important to highlight that if discussions raise any safeguarding issues, I will be required to contact the appropriate authorities.
- The more honest you can be in your answers the more it will contribute to the project.
- As you are participating as a group, please do not talk over one another and be mindful of giving everyone an equal opportunity to contribute.
- [Where applicable] We may have worked together on this project previously, but if you can answer the questions as if we're meeting for the first time that would be really helpful
- As a reminder we will be recording this interview.

START RECORDING

Warm up question

So for the recording, can I please ask you to introduce yourselves and please confirm you are happy to begin the focus group and to be recorded.

5. **I would like to start by exploring how this pilot came to exist and what your involvement was.**

1A. Please can you describe the model of care used in this pilot and why it was chosen?

Prompt:

- *Was this pilot in response to anything? What is its purpose?*
- *Do we already know that this model of care works in a primary setting?*
  - *Why base a link worker in secondary care?*
- *Difference between the link worker roles? Decision for the different type of link workers?*

1B. What has been your involvement / role in the pilot?

Prompts:

- *Set-up e.g., recruitment?*
- *Implementation e.g. referrals, support?*
- *How has the link worker role impacted you?*

6. **We are now going to move onto discussion about the anticipated and actual benefits of the link worker in pain clinic model of care.**

2A. I am aware that you may not yet be aware of the actual benefits this model of care will have for **healthcare providers**, but please can you comment on any expected or real benefits where known?

Prompts:

- Alleviation of burden on services?
- Evidence of changes to e.g., re-referral rates, GP, ED?
- Linking up with community assets (e.g., better links between primary , secondary and voluntary care). Has the link worker aided better communication / links between services?
- Shared learning?
- Any other benefits to healthcare providers?

2B. Again, I am aware that you may not yet be aware of the actual benefits this model of care will provide **patients**, but please can you comment on any expected or real benefits where known?

Prompts:

- Wellbeing? Physically / Emotionally?
- Ability to self-manage
- Clinical outcomes?
- Linking up with community assets
- Any other benefits for patients?

7. **Now I am going to ask you to reflect on the challenges and facilitators of the pilot.**

-

3A. Please can you describe any barriers experienced in this pilot?

Prompts:

- *E.g., at point of set up, deciding roles, recruitment, training,*
- *Implementation, recording data etc?*
- *Any other barriers?*
-

3B. What have been the facilitators?

Prompts:

- E.g., what has helped to mitigate The challenges you have mentioned?
-

3. Finally, I am going to ask a couple of questions around learning and areas of improvement following the pilot.

4A. What are the lessons learnt for implementing and delivering this model of care (link workers in pain clinics)?

Prompts:

- *Eligibility criteria?*
- *What worked well / not so well?*

- *Where and what improvements could be made?*
-

4B. What would support spread and adoption of this model of care?

Prompt:

- E.g., Capacity, Infrastructure, Flexibility in approach
-

Closing the focus group

That's all of the discussion points I wanted to cover.

Is there anything else that you would like to ask or any other comments that you would like to make before we finish the focus group?

Thank you for your time.

C) Topic guide for interviews with patients

Pre focus group procedures

- Thank you for agreeing to participate in this interview.
- This interview is part of the Link Workers in Pain Clinic Evaluation which is being conducted by the Health Innovation Network**.** The evaluation aims to understand the benefits of and ways to improve the link workers role within pain clinics with the view to scaling up across Southwest London.
- My name is Kate, I work at the Health Innovation Network.
- Before we start, do you have any questions?

Introduction:

- Our interview today will be focusing on your experience of the link workers in pain clinic pilot. It should take no longer than 30 minutes.
- There are no right or wrong answers to questions.
- Everything you say is completely confidential and will be made anonymous.
- I ask that we make an agreement within the group that what we share within the group stays in the group.
- However, it is important to highlight that if discussions raise any safeguarding issues, I will be required to contact the appropriate authorities.
- The more honest you can be in your answers the more it will contribute to the project.
- As you are participating as a group, please do not talk over one another and be mindful of giving everyone an equal opportunity to contribute.
- As a reminder we will be recording this interview.

START RECORDING

Warm up question

So for the recording, can I please ask you to introduce yourself and please confirm you are happy to

begin the interview and to be recorded.

8. **I would like to start by exploring your journey with pain up to this point and how you came to know about the Health and Wellbeing Coach OR Social Prescriber.**

1A. How did you hear about the (link worker) and what information did you receive about them and/or what they could offer?

- *Prompts:*
    - *What resources were given to you? E.g., leaflets, poster, letter*
    - *What were your initial thoughts?*
    - *What were your expectations?*

1B. What influenced your decision to accept (or not accept) the referral?

Prompts:

- *What else had been tried? Why did you agree to the sessions?*
- *What do you think might prevent someone from accepting the help / referral?*

1C. What has been your experience of getting support with pain up until this point?

Prompts:

- *Experience of pain / duration / type?*
- *Have you used a pain clinic before?*
- *Have you worked with a Health and Wellbeing Coach or Social Prescriber for pain or another chronic / long term condition?*

9. **We are now going to move on to discuss your experience of working with the Health and Wellbeing Coach OR Social Prescriber.**

2A. The (link workers) typically offer up around 6 sessions, but I understand that this is personalised and amount of sessions / what is covered will vary. I just wants to get a sense from you, how many sessions you were offered and attended, how long they lasted, and what sort of topics were covered?

Prompt:

- Duration?
- Number of sessions?
- What happened in the sessions?

2B. Thinking about your time with the (link worker), how did you find the experience (what worked well, what didn't work so well) ?

Prompt:

- What did you like? What didn't you like so much?
- What might you want included? What could you have done without?

2C. What changes have you noticed in yourself since working with the Health and Wellbeing Coach OR Social Prescriber (anything positive or negative)?

Prompt:

- What has changed since engaging with the link worker? E.g., if you had not had your

sessions, how do you think your health and wellbeing would have been affected?

- Wellbeing? Physical / Mental health changes?
- Ability to self-manage? Change in behaviour?
- What will you take away from your time with the link worker?

2D.How (if at all) did the sessions with the Health and Wellbeing Coach OR Social Prescriber change the way you interacted with other healthcare providers?

Prompt:

- Reduction in use of other services? E.g., if you had not had the support from the link worker, would you have sought support from elsewhere?
- *Which services were you put in touch with via your link worker?*

10. As you may know, the sessions with your Health and Wellbeing Coach OR Social Prescriber were all part of a pilot to understand and improve this role in pain clinics, with a view to expand the service across Southwest London.

-

3A. With this is mind, what changes or improvements would you like to see?

Prompts:

- *Content / stucture of sessions?*

Closing the focus group

That's all of the discussion points I wanted to cover.

Is there anything else that you would like to ask or any other comments that you would like to make before we finish the interview?

Thank you for your time.

D)Topic guide for interviews with patients Anonymous Patient Satisfaction

Chronic Pain Self Management Team
Satisfaction Survey

We would be grateful if you could complete this satisfaction survey as it will help us to continue to improve our service. Your feedback is anonymous. Many thanks.

1: How satisfied were you with information you received before your first session? (E.g., explanation of the service or information on what to expect)

- ☐ Extremely Satisfied
- ☐ Mostly Satisfied
- ☐ Neither Satisfied Nor Dissatisfied
- ☐ Mostly Dissatisfied
- ☐ Extremely Dissatisfied

2: How satisfied were you with the organisation of the sessions? (E.g., ease of making appointments, time given to discussions)

- ☐ Extremely Satisfied
- ☐ Mostly Satisfied
- ☐ Neither Satisfied Nor Dissatisfied
- ☐ Mostly Dissatisfied
- ☐ Extremely Dissatisfied

3: How were your appointments conducted?

- ☐ In Person
- ☐ Virtually or by Telephone
- ☐ A combination of In Person appointments and Virtual/Telephone appointments

4: How satisfied were you with the sessions? (E.g., covered what you had agreed would be covered and the content was relevant to you)

- ☐ Extremely Satisfied
- ☐ Mostly Satisfied
- ☐ Neither Satisfied Nor Dissatisfied
- ☐ Mostly Dissatisfied
- ☐ Extremely Dissatisfied

5: How satisfied were you that the professional delivering the sessions had the skills to help you address your concerns?

- ☐ Extremely Satisfied
- ☐ Mostly Satisfied
- ☐ Neither Satisfied Nor Dissatisfied
- ☐ Mostly Dissatisfied
- ☐ Extremely Dissatisfied

6: How satisfied were you with how you were treated? (E.g., feeling listened to and treated with respect).

- ☐ Extremely Satisfied
- ☐ Mostly Satisfied
- ☐ Neither Satisfied Nor Dissatisfied
- ☐ Mostly Dissatisfied
- ☐ Extremely Dissatisfied

7: Please tick any of these strategies that you have found helpful:

☐	Goal Setting Plans	☐	Diaries / Journals
☐	Information Sheets	☐	Homework
☐	Schedules / Timetables	☐	Links to Websites or Podcasts
☐	Signposting to Additional Organisations	☐	Suggestions for Further Reading

8: What was your overall experience of the service?

- ☐ Extremely Positive
- ☐ Mostly Positive
- ☐ Neither Positive Nor Negative
- ☐ Mostly Negative
- ☐ Extremely Negative

9: Do you have any additional comments about the service?

Comments:

Thank you for providing your feedback. Your views are important to help improve our services.

If you would be interested in completing a focus group to further share your experience of the service, please provide the following information:

Name:

Email address:

Contact number:

E) Measure Yourself Concerns and Wellbeing (MyCaw) form

Today's Date:_____

Please tick the relevant boxes below so we can understand more about the data collection:

I am a: (please tick)

☐ Client completing this on my own

☐ Carer completing this about myself

☐ A carer supporting someone to complete this (e.g. family member)

This was completed: (please tick)

☐ During a face-to-face appointment

☐ During a phone/ video consultation

☐ At home, returned by post

☐ Via an online survey

☐ A professional supporting someone to complete this (e.g. nurse or link worker)

Please write down one or two concerns or problems which you would most like us to help you with.

1.

2.

Please circle a number to show how severe each concern or problem is now:

This should be YOUR opinion, no-one else's!

Concern or problem 1:

☺ 0 1 2 3 4 5 6 ☹

Not bothering me at all

Bothers me greatly

Concern or problem 2:

☺ 0 1 2 3 4 5 6 ☹

Not bothering

Bothers me

me at all greatly

Wellbeing:

How would you rate your general feeling of wellbeing now? (How do you feel in yourself?)

☺ 0 1 2 3 4 5 6 ☹

As good as it could be — As bad as it could be

Thank you for completing this form

Measure Yourself Concerns and Wellbeing (MYCaW®)

Today's Date: _____

Please tick the relevant boxes below so we can understand more about the data collection:

I am a (please tick):

☐ Client completing this on my own

☐ Carer completing this about myself

☐ A carer supporting someone to complete this (e.g. family member)

This was completed: (please tick):

☐ During a face-to-face appointment

☐ During a phone/ video consultation

☐ At home, returned by post

☐ Via an online survey

☐ A professional supporting someone to complete this (e.g. nurse or link worker)

Look at the concerns that you wrote down last time (please do not change these).
Now circle a number below to show how severe each of those concerns or problems is now:

Concern or problem 1:

☺ 0 1 2 3 4 5 6 ☹

Not bothering me at all — Bothers me greatly

Concern or problem 2:

☺ 0 1 2 3 4 5 6 ☹

Not bothering me at all — Bothers me greatly

Wellbeing:

How would you rate your general feeling of wellbeing now? (How do you feel in yourself?)

☺ 0 1 2 3 4 5 6 ☐

As good as it could be — As bad as it could be

Other things affecting your health

The support that you have received here may not be the only thing affecting your concern or problem. If there is anything else which you think is important, such as changes which you have made yourself, or other things happening in your life, please write it here.

What has been most important for you?

Reflecting on your time with us what were the most important aspects for you?

Thank you for completing this form

MYCaW® User notes:

MYCaW® requires users to hold a licence for use which can be obtained from Meaningful Measures Ltd. Please contact www.meaningfulmeasures.co.uk or email: helen@meaningfulmeasures.co.uk

MYCaW® CANNOT be freely reproduced and used unless users have a licence.

The layout and wording of MYCaW® should not be changed. The exception to this is at the top of the first form there is space to add extra identification questions, such as an ID number, or the name of the

therapy or session being seen. These can be added above today's date - but check the layout of the rest of the form does not get altered by this. You may add the name of your centre as a header. MYCaW® can be administered via: In person face-to-face, by a person on their own, via post, phone/video call, online. Please see below for full instructions.

First form

1. It is very helpful to capture who has filled in the form - if it is not the client or patient. We know that some people with communication difficulties may need some help completing the form, so others can complete it for them, but show that they are doing it on behalf of others by selecting the relevant box.

2. The first form is best completed with some guidance and encouragement. This may be within an assessment or consultation, and usually fits in best near the end of this.

3. The client/patient should be encouraged to choose their own concerns and write them in their own words. You may write their words down if they wish but it must be verbatim and in the first person. i.e. "I have a pain in my arm". Where possible they must be given the pen to do the scoring themselves.

4. Make sure that each problem or concern is stated separately. For example: "pain and not sleeping" should be split into two. This is because one may improve but not the other, and then subsequent scoring is difficult.

5. Scoring must involve circling one number or entering a whole number digitally. Halfway between numbers is not allowed.

Follow-up form

In the last question on the follow-up form you can enter the name of your centre or appropriate wording instead of the word "us".

When people complete the follow-up form, people need to have their previously chosen concerns in front of them, however, they must not see what scores they gave the first time. This can best be done in one of the following ways:

1. **In person face-to-face:** If the follow-up form is being done with guidance, the front page of the original first form can be shown to the respondent or concerns can be read to the client from a screen, while he/she fills in the follow-up form. People with communication difficulties can be assisted by a proxy carer.

2. **If completing on their own, or via post**: If the follow up form is being completed without the need for guidance, either in the centre, or posted to the respondent's home, then the completed front page of the first form can be photocopied onto the blank side of the follow-up form (or a copy could be stapled on if this is easier). The follow-up form (self-completion version) will then have the respondent's original concerns in their own handwriting on one side and a form to score them again on the other side. People with communication difficulties can be assisted by a proxy carer.

3. **Over the phone or via video consultation:** MYCaW® cannot always be administered in person and we appreciate that many appointments are via telephone or video consultation.

Please ensure that people filling in MYCaW® have a copy of the questions in front of them if possible when carrying out the data collection.

Please ensure that all responses are the exact words of the respondent. Please repeat back what you have written down in the boxes to the respondent at the end of data collection to ensure they are happy with what has been written.

Please be aware that clients or patients who have cognitive difficulties, are deaf or hard of hearing, who

have had a stroke or have dementia, may be unable to complete this over the phone/ video call. Instead a carer could help fill in the questionnaire – if so reflect this by ticking the box as to who has completed the form.
The follow-up form can be posted or emailed, and this can also be completed over the phone/video call.

4. **Online via electronic platform/ survey:** As above for the 'not in person' instructions. Original first form and follow-up forms can be administered via online survey platforms. Please contact Meaningful Measures for further support. People with written communication difficulties can be assisted by a proxy carer.

MYCaW® Scoring Guide

Concern 1, Concern 2 and Wellbeing each have a separate score, between 0 and 6. It is also possible to compute a MYCaW® profile score, which is the mean of these scores. For example, if Concern 1 is scored 5, Concern 2 is score 3, and Wellbeing is scored 2, then the MYCaW® profile is 10/3 = 3.3.
It is recommended that the MYCaW® profile score is accompanied by the other scores, to make it more meaningful.

F) Pain Self-Efficacy Questionnaire (PSEQ)

Instructions:

Please rate how confident you are that you can do the following things at present, despite the pain. To indicate your answer tap one of the options on the scale under each item, from "not at all confident" to "completely confident".

		Not at all Confident	1	2	3	4	5	Completely Confident
1	I can enjoy things, despite the pain.	**0**	**1**	**2**	**3**	**4**	**5**	**6**
2	I can do most of the household chores (e.g. tidying-up, washing dishes, etc.), despite the pain.	**0**	**1**	**2**	**3**	**4**	**5**	**6**
3	I can socialise with my friends or family members as often as I used to do, despite the pain.	**0**	**1**	**2**	**3**	**4**	**5**	**6**
4	I can cope with my pain in most situations.	**0**	**1**	**2**	**3**	**4**	**5**	**6**
5	I can do some form of work, despite the pain. ('work' includes housework, paid and unpaid work).	**0**	**1**	**2**	**3**	**4**	**5**	**6**
6	I can still do many of the things I enjoy doing, such as hobbies or leisure activity, despite pain.	**0**	**1**	**2**	**3**	**4**	**5**	**6**
7	I can cope with my pain without medication.	**0**	**1**	**2**	**3**	**4**	**5**	**6**
8	I can still accomplish most of my goals in life, despite the pain.	**0**	**1**	**2**	**3**	**4**	**5**	**6**
9	I can live a normal lifestyle, despite the pain.	**0**	**1**	**2**	**3**	**4**	**5**	**6**
10	I can gradually become more active, despite the pain.	**0**	**1**	**2**	**3**	**4**	**5**	**6**

Developer Reference:

Nicholas, M. K. (2007). The pain self-efficacy questionnaire: Taking pain into account. European Journal of Pain, 11(2), 153-163.

Administer Now

Page 1 of 1