THE ROLE OF PATIENT PARTICIPATION GROUPS (PPGS) IN SOCIAL PRESCRIBING

(PPGS PERSPECTIVE ON AWARENESS AND COLLABORATION WITH LINK WORKERS)

MAY 2022

National Association of Link Workers

National Association for Patient Participation

Acknowledgement

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Introduction

In conjunction with the National Association for Patient Participation (NAPP) founded in 1978, NALW conducted research with patient participation groups (PPGs). N.A.P.P is the only independent voluntary organisation in primary care working with GP practices to promote quality of care for all patients. N.A.P.P champions the patient voice in issues of healthcare, policy development and academic research, working with politicians, policymakers, health professionals, academics, voluntary groups, and the general public. NALW is the sole professional body for Social Prescribing Link Workers (SPLWs) in the UK and promotes confidence and integrity in the profession by ensuring patients and communities receive high quality social prescribing services. NALW members commit to high quality social prescribing professional practices and standards through Continuing Professional Development (CPD) and adhering to the NALW code of practice.

This report will give an overview of PPGs and SPLWs, the context, background, and rationale behind this research. We will then continue to review the results of the NAPP survey, key findings, recommendations, and conclusion.

What are PPGs?

PPGs are grassroots organisations first established in 1972, that meet to discuss practice issues, and patient experience and to share this information with practice staff to help improve the service provided. A PPG is usually comprised of patients with an active interest in health, carers, and staff from the local practice. Since April 2015, practices in England have had a contractual obligation to have a PPG and for it to be representative of the practice population. All communities, groups, genders, ages, ethnicities, and disabilities representing the patient list are encouraged to join, the only requirement is that they must be a patient registered with the practice.[12]

What are SPLWs?

The Social Prescribing Link Worker (SPLW) is a non-clinical frontline healthcare professional, with a focus on improving the health and wellbeing of individuals and communities through preventative care, social justice, the reduction of health inequalities and an understanding of the wider (social, economic, and environmental) determinants of health and the role communities plays in health and wellbeing. They give people time to talk about what matters to them.

SPLWs recognise that the context of people's lives determines their health. Operating holistically and proactively, SPLWs identify socio-economic and environmental factors that impact health and supports patients to access the appropriate support and interventions. Through personalised care approaches and working in partnership with the individual they ensure barriers to care are identified and minimised[13].

SPLWs also ensure that patients/clients have the right support system and strategies they need for better wellbeing. They are a key link between the healthcare system and the community, ensuring that vulnerable people are able to access care and support during the pandemic and beyond.[8]

Context and Background

The 1978 Declaration of Alma-Ata made several key recommendations,[1] including that people have a duty and a right to participate individually and collectively in the planning and implementation of their health care. A further recommendation was that primary health care *"requires and promotes maximum community and individual self-reliance and participation in the planning, organisation, operation and control…making the fullest use of local, national and other available resources; and to this end develops through appropriate education the ability of communities to participate."* In line with the recommendations NHS England has stated that it is committed to working with and listening to patients, carers, and the public, and to embedding the patient and public voice in the commissioning process. [2,3]

Despite these recommendations, a statutory requirement for GP practices to have a PPG in place was only introduced in 2015[4], suggesting that the importance of public and patient involvement in primary care has only been recently adopted by the NHS in an official capacity. Subsequently, the potential for patient and public participation to transform the delivery of modern healthcare is yet to be fully realised.

Rationale and Method

Given this context, we conducted this research to fully understand the potential of PPGs to enhance healthcare, particularly regarding the role they can play in social prescribing and in conjunction with SPLWs. This research is part of an effort to increase the awareness of Social Prescribing Link Workers (SPLW) amongst PPGs and to understand how PPGs and SPLWs are collaborating. We aimed to identify areas of success and to better appreciate gaps in the working relationship that hold potential for improvement.

The survey was sent out to PPGs nationwide and ran from the 20th of January to the 15th of March 2022. We received responses from 120 different PPGs and have compiled these responses into the following report.

An encouraging takeaway from this research was that a significant proportion of PPGs knew what SPLWs do and were supportive of that work. While levels of collaboration were low, there was a significant amount of enthusiasm, interest and motivation sparked by the survey, with respondents reporting that they had contacted their SPLW as a result and others requesting guidance on how to collaborate with SPLWs. We found that many PPGs had their meetings suspended or heavily disrupted during the pandemic or were even closed altogether. The interest from the survey suggests that social prescribing and SPLW could act to remobilise PPGs to action in the postCOVID-19 period.

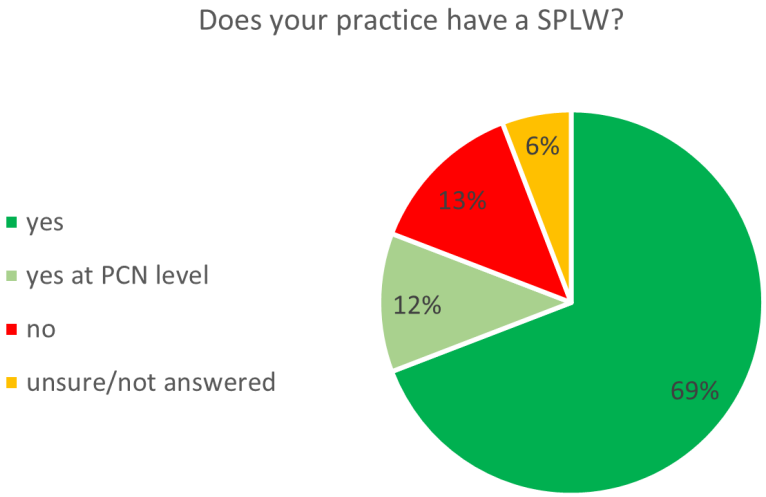
Another encouraging finding was that a large proportion of PPGs (81%) had SPLW affiliated with their practice or PCN. There were several excellent examples of good practice and effective collaboration working which we have outlined in our good practice case studies. There was also a significant number who had not been able to collaborate due to the pressures of COVID-19.

Overall, there is an acute need to recruit more SPLWs, raise awareness of their role and facilitate collaboration with PPGs which we have highlighted in our recommendations.

Results of the Survey

120 PPGs were surveyed between the 20th of January and the 15th of March 2022 – PPGs surveyed were for the most part based in England, with a few from Wales and Scotland. Responses to the key questions from the survey are displayed below.

1 Does your practice have a social prescribing link worker (also called a social prescriber)?



81% of PPGs surveyed reported that they have an SPLW affiliated with their practice, either directly or at a PCN level. On the surface, this is an encouraging statistic, however, 15% of practices who answered yes to this question share an SPLW with multiple practices. According to research by GPonline, the average GP practice list is 9,000 patients, a 30% increase in the past seven years.[5] This is in line with NHS Digital General Practice Workforce Statistics[6] which report an average of 9,444 patients per GP practice. Simultaneously, the number of GP practices is falling, due to mergers, staff shortages, retirements or CQC closures. What this means is that SPLWs shared across practices are responsible for serving a population in the tens of thousands. One SPLW was reported by a PPG to be shared across 6 practices in a PCN, around 57,000 patients.

"Yes, but she is shared across all 6 Practices in our PCN."

"Yes, shared across all the practices in our area."

"Yes but for the whole of the PCN to share."

"Yes, Our practice has a link worker for Social Prescribing. This is a shared post across 3 surgeries in our PCN."

"2 Social Prescribers shared across two Practices employed by our Primary Care Network."

It is encouraging to note that beyond collecting information, the survey itself prompted engagement, demonstrating the value and enthusiasm amongst PPGs for the service that link workers can provide. One recipient of the survey was subsequently moved to make enquiries to find out if they had a local SPLW. Once found, the SPLW immediately offered to set up a meeting.

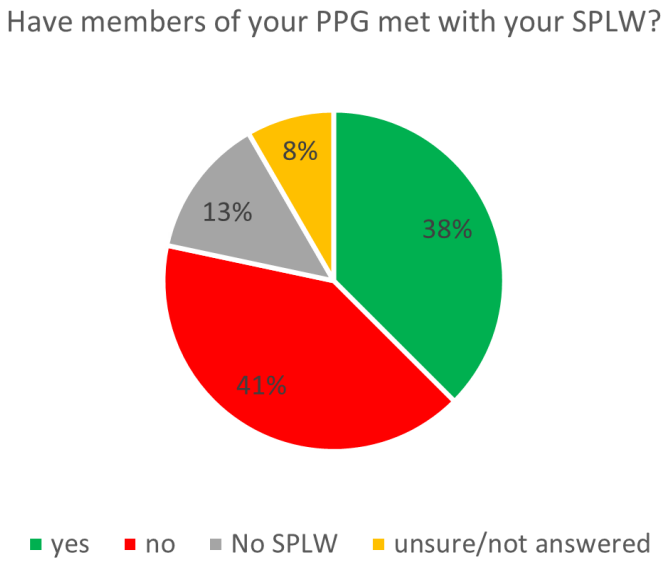
"We believe so - but only just had info following sending this email to them. Offering to hold a joint meeting for the end of March."

Other PPGs were not even aware that they had link workers

"We have only very recently discovered that our medical centre has two social prescribing link workers funded by the CCG. These are shared between the two practices who have around 35,000 Patients between them."

This reveals the importance of understanding and communication between PPGs and SPLW to realise the full potential of the service.

2 Have members of your PPG met with your SPLW?



While 81% of recipients reported that they have an SPLW, the number who have met their SPLW is far lower. Less than 50% of the PPGs with an SPLW have met with them. Reasons for this vary.

Many PPGs have not met due to COVID-19 restrictions:

"No due to age and health of existing members and lack of interest of others, we are not currently holding meetings"

"No not yet due to Covid. We have heard many examples of the value she is bringing and how she is appreciated by patients, from the surgery staff."

"It's been a difficult time for one-to-one meetings but members of PPG have provided links to voluntary organisations and local initiatives i.e. coffee mornings"

"Only limited contact due to COVID restrictions"

"Unfortunately, we haven't had a PPG meeting for some while but hopefully we can restart again this year."

Others due to administrative issues from PPGs dissolving or merging:

"All our PPG members have resigned or retired."

"We have a new PPG after seven sites merged into a 'super-partnership' so we haven't met the link worker(s) yet but have plans to meet and include the role in our monthly bulletins."

Of those that had met with the SPLW, 20% of those meetings were virtual, through programs such as Zoom/Teams or telephonic. While remote working tools allow for meetings during times of COVID restrictions, there are many benefits of face-to-face meetings. Communication is more engaging when meeting face-to-face and it is easier to pick up on non-verbal social cues such as body language, facial expressions, and level of attention. These are particularly important for collaboration, innovation, building social capital, fostering connection, and building community.

"...much better if they're based in the same building!"

Hands-on action from PPGs and SPLW has led to some encouraging examples of success, one PPG group was invited to meet with the SPLW as soon as they were appointed and have arranged a follow-up meeting. Another reported that they had received two presentations from link workers and had collaborated closely with link workers in their area. Proactive, empowered PPGs appear to be associated with a better quality of relationship with their SPLW and better results for the communities they serve:

"We have always linked with the social prescribers because as a PPG we pushed hard for our practice to involve itself. This resulted in charity-sponsored social prescribers dedicated to our practice for about a year."

"The PPG Committee (4 PPG members) were invited to meet the Social Prescriber as soon as she was appointed."

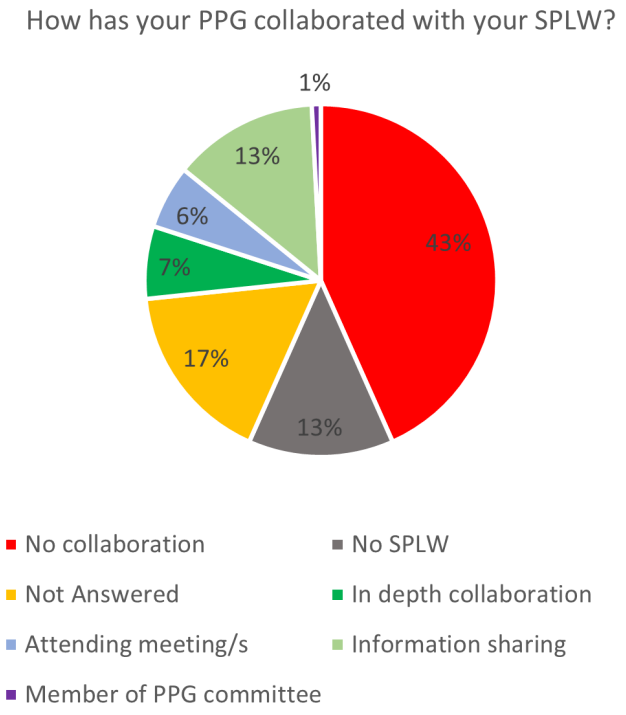
"Our committee members met our social prescriber by invitation to one of our meetings. She accepted an invitation and stayed for the whole meeting...we have an open line to our social prescriber."

It is also worth noting that the survey demonstrated the presence of enthusiasm once again, prompting engagement from recipients.

"Yes, we have but it was a while ago and has reminded me to invite them again as only 2 people remembered."

"No, but that's a good idea"

3 Please describe how your PPG has worked collaboratively with your SPLW



Only 27% of recipients reported any kind of collaboration between PPGs and SPLW. The most common answer was that no collaboration of any kind had taken place. COVID-19 restrictions around meetings appear to be a major factor in this, stopping face to face meetings from taking place or stopping PPGs from meeting altogether. Furthermore, the pandemic has placed an unprecedented level of pressure on GPs and primary care in general, which respondents reported precluded any collaborative efforts between PPGs and SPLW.

"I don't feel that there is a connection to enable the PPG to work with the person. We've met her on a Zoom link but that is all. The GP practice doesn't seem to encourage the link between the link worker and our PPG."

"The Pandemic has impeded any collaborative opportunities to work."

"Covid has prevented any progress"

"It has not been possible to develop any involvement by our PPG into this area due to the overriding priority of the practice in responding to the demands of the pandemic."

"The PPG has been unable to develop a working relationship with Link Workers as the Practice's absolute priority is to continue to treat patients throughout the pandemic."

Of those that did report collaboration, the most common form was information sharing about services such as clubs, groups, and charities in their local area:

"Any information given by PPG members, or indeed any patient, on activities in the local community, are passed to the SPLW."

"Our PPG had compiled a detailed list of clubs, charities and support groups prior to the appointment of the Social Prescribers by the PCN as an aid to the clinicians in the Practice. This is now used by Social Prescribers and is being updated currently to take account of changes enforced by Covid restrictions."

"The PPG invited the practice Social Prescriber Link Worker to their meeting in September 2019 to explain all about Social Prescribing and following that meeting, the PPG provided lists of all the local community voluntary groups with contact details, that were running at that time in the area."

"Our PPG liaised with our Social Prescriber throughout the 1st Covid lockdown regarding all the voluntary help available for patients within the practice catchment area."

"PPG include them on their email network linking to local groups & organisations serving the area exchanging information on health & wellbeing, events etc.

The second most reported form of collaboration was attending meetings:

"Wellbeing Coordinator also comes along to our PPG Golden Agers Coffee morning to talk about what they can do, answer questions etc."

"We haven't {collaborated} but they come to all of our PPG meetings."

In one interesting case, the SPLW has become a member of the PPG committee, a move that appears to facilitate the identification of clients in need in conjunction with a wellbeing co-ordinator

"They sit on our PPG board. Our new prescriber will work with our Wellbeing Coordinator to help individual clients."

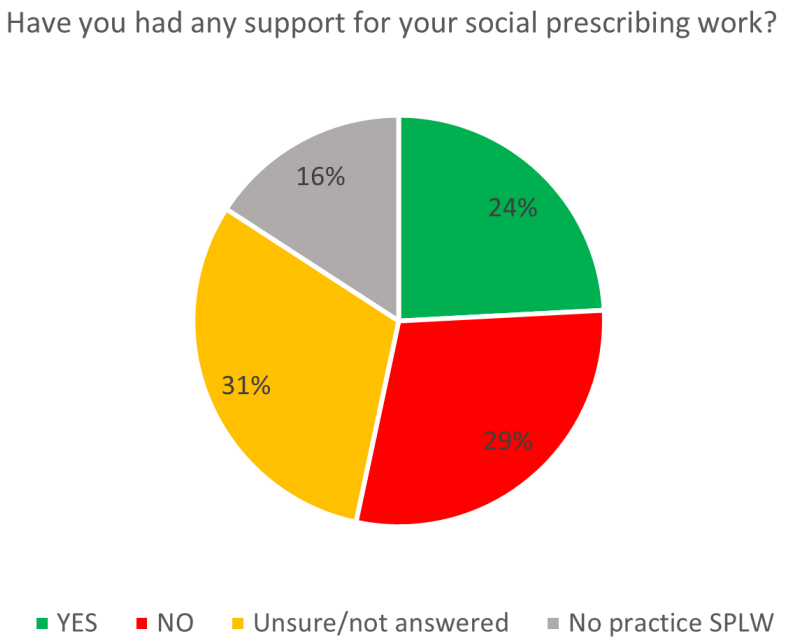
One potential barrier to effective collaboration appears to be a lack of clarity on how PPGs could collaborate with SPLWs and what SPLWs do, while these were in the minority, imprecision can lead to confusion and a lack of engagement despite the evident enthusiasm from PPGs in the benefits that social prescribing can offer.

"We have not worked collaboratively yet... we have arranged to speak again in April 2022 with a view to understanding what the PRG may be able to offer support or invest energy into relevant community projects e.g. befriending services, young person's health etc. It would be useful to see a case study of how other Practices have collaborated with their SP as a guide."

"At a recent meeting of our PPG, the Social Prescribing team of 3 came to introduce themselves and outline their roles. When asked how PPG could support, the 'lead social prescriber' gave a vague response which eventually became 'spread the word' upon further discussion. The other link workers were rather more precise about their roles."

Raising awareness through promotional material, meetings in which SPLW explain their role, case studies and models shared with PPGs could assist with collaborative efforts, providing a blueprint for the forms of assistance that SPLW could give to PPGs and practices and how they could work together.

4 Have you had any support for your social prescribing work?



This was a poorly understood question. Most recipients reported that they did not know what this question was asking. Of those that reported receiving support for social prescribing work this ranged from support, help with funding, training and attending meetings

YES, Both PPG members, medical staff and social prescribers have attended the 'Collaborative Practice' course

"Verbal support from PPG members including GP"

"Yes – funding to recruit Social Prescribers at PCN level"

"Yes – PPG meeting attendance"

"Yes- MDT meeting."

"The Practice has been very supportive, and some funding has been available from the Regional CCG."

"We have a team of 5 staff involved in social prescribing across our PCN patient population of c.50k. They work very effectively and have been a huge support to GPs and practices, particularly during COVID and periods of lockdown that have affected the mental health and wellbeing of many patients."

Again, the survey prompted engagement from PPGs which is evidence of considerable enthusiasm for social prescribing:

"NO, but as a result of this questionnaire I shall invite them to our next PPG meeting"

"No - but I now have a contact email address!"

5 Can you describe what do you think link workers do?

Amongst survey participants, there was an encouraging level of knowledge about the role of link workers. Most were able to describe the role of the SPLW in detail and only a minority of recipients had no idea.

One particularly interesting response was:

"Helps those with problems that a pill will not cure. Stress through loneliness, lack of involvement. Guiding people to activities that might help their state of mind in time. Can afford more time than a doctor can to solve the problems."

The word cloud below is a graphical representation of the responses to the question, with the size of a word corresponding to how often it appeared in the answers given. This gives an idea of the common themes in PPGs impressions of the role that SPLW play. General themes present in the majority of answers were:

- Additional support in patients' lives related to non-medical issues.
- Taking a holistic approach to people's health and wellbeing/needs.
- Helping isolated people, in need of social contact/social participation to overcome feelings of loneliness.
- Signposting to non-clinical/medical groups, resources, and services.

Good practice case studies

In this section, we will highlight several notable examples of work done between PPGs and SPLWs which could act as a blueprint for future collaboration between SPLWs and PPGs.

Case Study 1: The power of meetings

In the below example there is a positive relationship between members of the PPG and the SPLW enhanced by familiarity through regular meetings which have resulted in an open channel of communication. This is further boosted by the SPLW's engagement in a walking group that acts as an informal meeting. The PPG reports bilateral sharing of information that helps each to fulfil their role to the fullest potential.

"Our surgery runs Walking for Health, which is coordinated in partnership with the Social Prescriber. She has also attended PPG meetings. We let her know if there is anything we are worried about when we have walked with a group. She can then follow these concerns, or positive steps, with the surgery.

As a volunteer with Walking for Health, she has been a great help. I trained as a Covid Champion, and she was a useful source of information as regards local support. I also fed information to her, which she disseminated to the surgery."

Case study 2: Setting up vital community projects.

In this example, the PPG and SPLW have set up a community gardening project and a transport initiative to help people get to their hospital appointments.

"The PPG has worked with the Social Prescriber to help set up a community garden/ allotment project. The Social Prescriber has also asked for assistance from our PPG Volunteer Driver Network (established to take people for COVID vaccinations) to assist with taking people for hospital appointments."

The PPG goes on to describe SPLW as

"a valuable link between the Patients and the Practice GP's...allow for certain aspects of health and social care to be dealt with by the Social Prescriber thereby taking pressure off GP's who can concentrate upon more serious cases."

Case study 3: Collaboration aided by close location.

In this case, the PPG chair has almost daily contact with SPLW. The SPLW is usually located in the medical centre which helps to foster a close working relationship. While this is not always possible for SPLWs, it demonstrates how effective collaboration is underpinned by a close working relationship, aided by SPLWs having a presence at the surgery.

"As PPG Chair I work on an almost daily basis with our social prescribers. We organise our health champions, set up a cancer support group, set up a military veteran's support group, organised Covid Clinic volunteers etc. etc.

As a PPG we work very closely with our social prescribers...Our social prescribers usually work in our Medical Centre and Our social prescribers also attend our regular PPG meetings. Both PPG members, medical staff and social prescribers have attended the 'Collaborative Practice' course."

Case study 4: Growing community projects benefitting patients

In this example, close working between the SPLW and PPG befriending initiative benefitted both parties. The PPG befriending service benefited from the support and referrals of the SPLW and the SPLW was able to visit clients at the befriending service. Eventually, the befriending service was able to apply for and receive charity status.

"When we formed a befriending service, the Social Prescriber worked in close association with us referring via a form on the Practice's website to those people who needed home visits...the Social Prescriber referred people to the group and when possible, came to interact with the people he referred which worked very well indeed. Working together with him was a real success and helped many patients."

Key findings of the survey

KEY FINDING #1

81% of PPGs report that they have SPLW affiliated with their practice, however many of these are shared across multiple practices at a PCN level.

KEY FINDING #2

COVID-19 has heavily disrupted the relationship between PPGs and SPLWs – Only 38% of PPGs have met their SPLW and of these, many of these meetings have been sporadic if at all.

KEY FINDING #3

There is a considerable level of enthusiasm amongst PPGs for social prescribing. Some survey recipients responded to the survey by proactively engaging with their SPLW.

KEY FINDING #4

Levels of support and collaboration between SPLW and PPGs are low. Many PPGs report not having an active, collaborative relationship with their SPLW due in part to the pressures of COVID-19.

KEY FINDING #5

It was encouraging to note that of the PPGs surveyed, most have an excellent grasp of what SPLW can do. Only 5% had reported that they did not.

Recommendations

We direct these recommendations to the Royal College of GPs, The British Medical Association, Primary Care Networks, Employers, Integrated Care Systems, General Practice, NHS, Commissioners, and other relevant stakeholders. PPGs and Social Prescribing Link Workers require urgent support to live up to their potential and help alleviate the pressure on the health service.

PPGs and Social Prescribing Link Workers utilised effectively have the potential to ease the burdens faced by the health service. PPGs can identify and respond to the needs of their patient population to the benefit of the practice and the wider community[2]. At a time when General Practices are closing and numbers of clinicians are falling, PPGs perform work that is time-consuming and labour intensive, resources that stretched practice staff currently do not have. Furthermore, the work performed by PPGs is done voluntarily and as such, their cost-effectiveness is a significant factor in their favour.

SPLW can play a vital role in remobilising PPGs (see recommendation 2) and easing the workload on GPs, which continues to significantly increase, both in consultation number, consultation length, and patient-facing clinical workload.[9] We find that these recommendations are of mutual benefit in the sustainability of general practice for all parties concerned and urge that the recommendations are urgently implemented.

Recommendation 1: Increased recruitment of SPLWs.

While most PPGs report access to SPLW. Many of these are shared across multiple practices and patient populations numbering in the tens of thousands. Several NALW reports have highlighted a lack of support, burnout was threatening retention and sustainability. There are several encouraging examples in which SPLWs are working closely with PPGs to good effect (See Good Practice Case Studies section). These instances demonstrate the potential for social prescribing to help realise the potential of PPGs and with concerted efforts to recruit SPLWs and fund their work in communities, these results could be replicated on a larger scale. When SPLW are thinly stretched, they are unable to have a meaningful relationship with PPGs.

Recommendation 2: Development support for PPGs is needed

PPGs need support to fully undertake their role. PPGs are composed of members of the public, volunteers and as such, there is room for improvement in their development as evidenced by some of the information we received from the survey. Some respondents asked for support on how best to work with SPLWs and asked for case studies and examples. One of the successful PPGs reported that the group members, medical staff and social prescribers had attended a collaborative Practice course, suggesting that formal training opportunities could play a valuable role in maximising the benefit of PPGs.

Recommendation 3: Increased awareness of SPLWs to remobilise PPGs post-pandemic.

As mentioned above, a high proportion of PPGs have an SPLW. However, levels of collaboration are low. This is due to several factors. As we have previously noted there are relatively low numbers of SPLW, responsible for large numbers of patients across multiple practices. In addition to this, responses suggest that in some cases, there is a lack of awareness of the availability of SPLW hindering collaboration. The survey was met with a considerable groundswell of enthusiasm amongst PPGs. This enthusiasm must be converted into action through the raising of PPG awareness about SPLWs and social prescribing services that can also help raise awareness amongst patients. Promotional material, meetings in which SPLW explain their role, case studies and models shared with PPGs are all possible ways in which awareness could be increased.

Recommendation 4: Encourage meetings between SPLW and PPG to increase collaboration.

As disruptions caused by the COVID-19 pandemic ease, it will be important to prioritise regular relationship and visibility-building activities such as meetings between PPGs and SPLWs. This will have several vital knock-on effects, including providing an opportunity for SPLW and PPGs to increase levels of collaboration in social prescribing activities such as in Case Study 1. Virtual meetings are a valuable tool to facilitate communication between SPLW and PPG while face-to-face meetings are also important, with a range of benefits that support effective collaboration. Employers should afford SPLWs time to build a relationship with PPGs.

Recommendation 5: Realise the value of PPGs and fully utilise them to benefit patients.

The above case studies demonstrate the immense value that PPGs can have. Despite this, PPGs are underutilised and, in some cases, have been shut down completely. One respondent to the survey reported that their PPG was unilaterally dissolved by their parent practice and replaced with suggestion boxes, calls for volunteers and occasional focus groups.

PPGs, like other voluntary groups, are a valuable public health intervention. Aside from their primary function, they act as support groups, helps alleviate loneliness, and provide community intelligence. Importantly, participation in voluntary services has been associated with increases in mental and physical health, life satisfaction and social wellbeing.[10,11]

Every year N.A.P.P has given awards – the Corkhill award – to PPGs who do outstanding work that can be easily replicated by others. A review of these awards show that they are mainly for projects that would now be described as aspects of social prescribing long before the term social prescribing became widely used.

Conclusion

COVID-19 has heavily impacted all aspects of community health. There have been massive pressures on General Practice and the NHS in general throughout this time. SPLWs were no different and were immediately focused on supporting vulnerable and isolated patients throughout the pandemic, a vital role that they continue to fulfil. As a result of the pandemic, even more people are needing the support that SPLWs provide. With small numbers of SPLWs responsible for large caseloads across PCNS/ multiple practices and 20% of PPGs with no/uncertain access to an SPLW, it is understandable that their work has been negatively impacted. Ultimately, training and recruitment of more SPLW is a major priority for the profession's full potential to be realised. A lack of support risks link worker burnout and poses a serious risk to the sustainability of the profession.[7] In general, as numbers of clinicians fall[6] and workload increases[9] new models of healthcare that integrate non-clinical staff, such as SPLW, and community assets, such as PPGs, are vital for the future of community health. Prioritising the recruitment of SPLW, the mobilisation of PPGs and stimulating effective collaboration between these groups therefore must be a priority.

"If social inequalities are to be redressed then more SPLWs need to be trained, recruited, and utilised in the fight against inequality." [8]

According to the results of our survey, collaboration levels between PPGs and SPLWs are low however enthusiasm levels are high. To foster greater levels of collaboration, meetings should be prioritised where safe and practical. Virtual meetings tools are useful, however, in creating a collaborative relationship that is built on trust, community and the accumulation of social capital, the importance of face-to-face meetings is stressed. It is important to note that in all our successful case studies, effective collaboration was underpinned by good communication and working in close contact. In a time when the health service requires disruptive thinking and innovative solutions, the value of PPGs must not be underestimated.

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THE ROLE OF PATIENT PARTICIPATION GROUPS (PPGS) IN SOCIAL PRESCRIBING

(PPGS PERSPECTIVE ON AWARENESS AND COLLABORATION WITH LINK WORKERS)

FOR FURTHER INSIGHT
OR SUPPORT
PLEASE CONTACT THE AUTHORS

National Association of Link Workers

National Association for Patient Participation