Citizens Advice Liverpool

# Liverpool Advice on Prescription Service

# Report on the Respiratory Pilot May 2018 – January 2019

# Health Foundation/Innovation Fund

***Testing and reviewing the effectiveness of delivering Advice on Prescription (AoP) as part of the respiratory services redesign***

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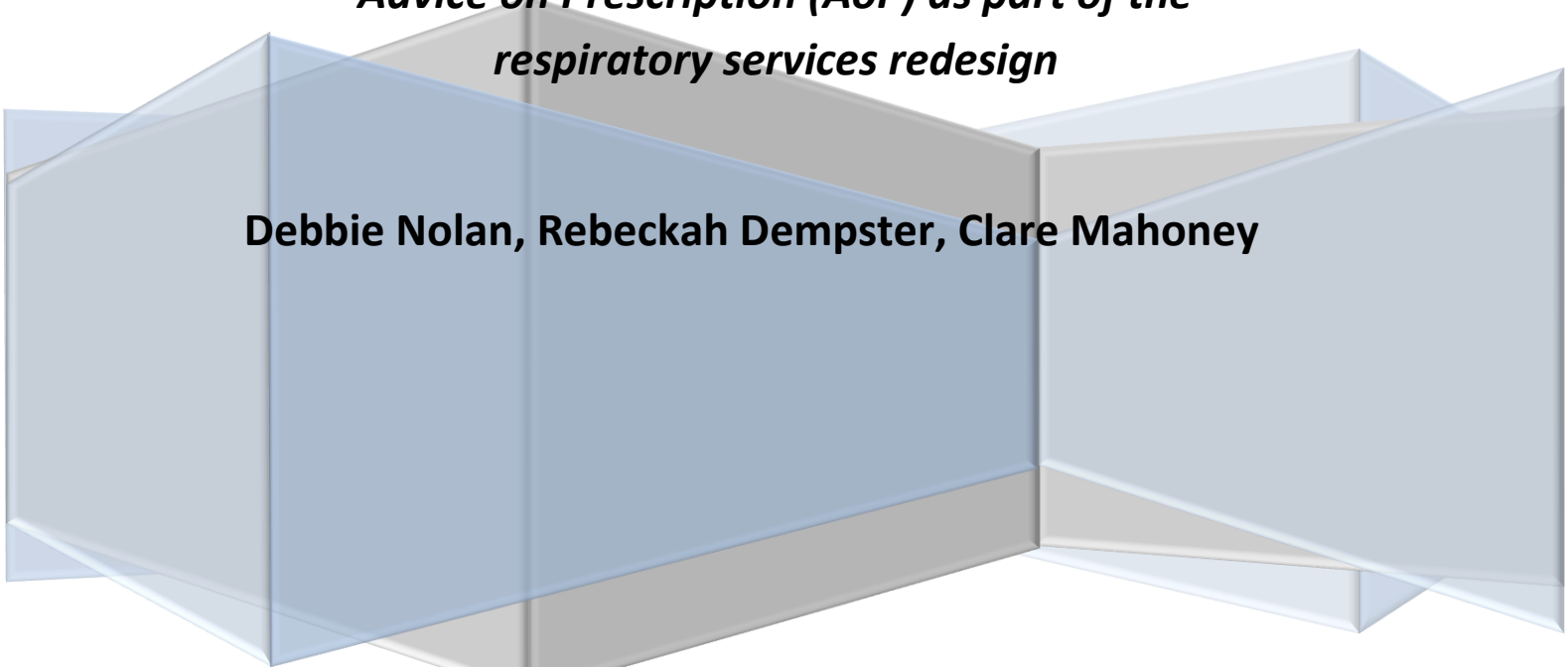

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## Summary

This report describes how in 2018 Citizen's Advice South Liverpool worked with local hospital services to test an integrated response to the wider determinants of health as part of respiratory services redesign. During the period of May 2018 to January 2019, 235 patients were referred for support. Typically those referred were dealing with high levels of anxiety and isolation and multiple health conditions, as well as many material privations. The pilot uncovered significant unmet need: 44.5% of those referred had an income of less than £800 pcm, and this figure reduced to 25.6% after support from the service. Each referral resulted in an average increase to household income of almost £2,900 pa, and an average reduction in debt by £346 pa. Levels of in-work poverty meant that some patients presented to the service unable to afford prescription charges, food or fuel. Citizen's Advice staff worked with groups of patients to highlight the value of maximising household income as a means of maintaining health and promoting money management and effective budgeting skills to ensure that the costs of heating and eating at least one hot, nutritious meal a day were covered. Clinical staff actively supported the pilot, reporting that they found it easy to refer and they saw that it resulted in immediate practical health and well-being benefits in their patients. Citizen's Advice Liverpool is currently working with Liverpool CCG to continue and sustain this service, which has currently been extended until March 31st 2019.

> *That's great news, which I have forwarded to the respiratory and heart failure service. Can it be spread to other services, I am just thinking of the HIV and TB services that I also support?*
> Jane O'Connor, Lead Nurse Community Services, Liverpool Heart & Chest Hospital Trust

## Introduction

The *Liverpool Advice on Prescription* project run by Citizen's Advice South Liverpool, was set up in 2014 in order to help alleviate poverty and hardship among people with long-term conditions and/or co-morbid mental health problems. The service takes direct referrals from GPs and mental health services, responding to urgent need as well as providing practical advice and support. Confident that the service was having a positive impact on outcomes for patients, Liverpool CCG and partners asked what else could be done to reach vulnerable patients and help remove barriers to health and wellbeing. Should the service offer be targeted along additional health and care pathway and if so which ones?

Determining that a greater understanding of the relationship between illness and social and economic hardship in the Liverpool context was needed, three main objectives were agreed:

1. To link person-level data from clinical and social case-management systems
2. To conduct a preliminary analysis of linked data
3. To test out and evaluate the effectiveness of the model in an acute care setting.

This report relates to objective 3 and summarises the learning from the testing out of the *Advice on Prescription* intervention in services along the respiratory care pathway. Objectives 1 and 2 are addressed in a separate report.

Testing out the delivery of *Advice on Prescription* as part of respiratory services redesign in Liverpool was agreed because the literature showed that rates of unemployment were higher among people with lung disease. We suspected that there might be unmet need in people with respiratory conditions and wanted to know whether the *Advice on Prescription* model could be developed to find and address this need.

### Case Study One

The patient lives alone. She has multiple health conditions including COPD and lung disease and was referred for welfare benefits advice. A welfare benefits check was provided and the patient was assisted with a successful application for Attendance Allowance, which increased her income by £113 a week. She was also supported to secure a 'Blue Badge' for parking purposes. The patient has increased her income by over £5,800 p.a. and also increased her accessibility to activities and services as she now has a Blue Badge.
The nurse who referred said, she was 'very happy with the service' and that the patient had said*: "I feel like I've got my life back again".*

## The Initial Phase

The project began in April 2018 with listening and relationship-building. Respiratory services are provided by three different hospitals, Mersey Care, Royal Liverpool University Hospital, and Liverpool Heart and Chest pulmonary rehabilitation. In discussion with the commissioning manager for respiratory conditions, the following services were given priority initially:

- Pulmonary Rehabilitation Service Team (PRST) which is based in Liverpool Heart & Chest Hospital (LHCH) and provides rehabilitation services in hospitals and in seven community

settings. The team is made up of 11 members, comprising five physiotherapists, three exercise psychologists and three health care support workers providing services to approximately 800 patients each year.

- Community Respiratory Team is based in Liverpool Royal Hospital treating those with more acute breathing symptoms both in the community and to support hospital discharge.

Initial meetings between the Pulmonary Rehabilitation Service Team and *Advice on Prescription* representatives we designed to:

- Provide key members of the Pulmonary Rehabilitation Service Team (PRST) with an overview of the *Advice on Prescription* Service
- Introduce the proposed 'test and learn' project
- Discuss and agree a referral pathway from the PRST to *Advice on Prescription*

*Advice on Prescription* staff introduced key staff from within the PRST to their practical service offer with its focus on wider determinants of health inequalities. The key functions were described as follows:

- Alleviating economic and social hardship among people with long-term conditions and/or co-morbid mental health problems.
- Providing a social treatment option: benefits, financial hardship/insecurity, homelessness, debt, relationship breakdown, bereavement, domestic abuse, unemployment, fuel poverty.

As a result of these initial meetings with clinical services, it was agreed that a trained advisor from the Liverpool *Advice on Prescription* service would provide training and on-going liaison to staff working in one hospital setting (LHCH) and seven community settings providing the Breathe Programme[i]. Respiratory care professionals were supported to use routine enquiry to screen for practical needs, and where appropriate refer to the Liverpool *Advice on Prescription.* The *Advice on Prescription* would make the initial assessment and provide advice, support and advocacy as required by the patient. Follow up advice and support to be available from a wide range of venues as per patient choice.

Patients referred receive an initial telephone call and either an appointment for face to face or telephone advice if appropriate or if the patient is housebound and the GP makes home visits we have facilitated this need. All patients referred are offered a benefit check and advice on a wide range of issues. On many occasions initial advice resulted in follow up appointments for further advice and assistance with applications for benefits and grants.

In October 2018, the *Advice on Prescription* service was expanded to provide a fully comprehensive social prescribing offer: *Ways to Wellbeing Liverpool* and patients referred to the service were able to

receive support from a link-worker in accessing a range of social and wellbeing services within the community.

## Case Study Two

Referred to AoP by the Respiratory Rehabilitation Team a 62 year old woman, living alone in social housing was living on an income of £123 per week (£533 pcm). Patient has severe and complex health problems - COPD and lung cancer, anxiety and depression. Very low mood, low confidence and socially isolated. Was struggling to manage her household expenditure and unable to heat her home properly. Given support applying for Attendance Allowance and associated disability premium and pension credit. Her income increased by £121 per week to £244 - (£1057 pcm). At the last appointment the client mentioned she had just finished her last week of her 10 week Breathe course and did not know what to do next, she said that she was interested in becoming a volunteer in a local centre that was looking for someone to cook for them but did not want to travel far. Advice on Prescription supported the client to get involved in community activities as part of its social prescribing offer. Client has low confidence, and her personalised wellbeing plan identified need for support coping with stress and building confidence. She attended a confidence course and is now volunteering for the charity, and has started an exercise class near where she lives.

## Activity and Outcomes

Referrals to the service began in May 2018 with indications of steady but relatively slow take up. The hospital group numbers were very small but generated referrals as all patients who were involved in the service promotion sessions were referred for advice and support. As the team was developing service awareness within the community rehabilitation teams, they also connected with clinical nurse specialists in The Royal Liverpool Hospital (Community Respiratory Team) who began referring their most vulnerable clients.

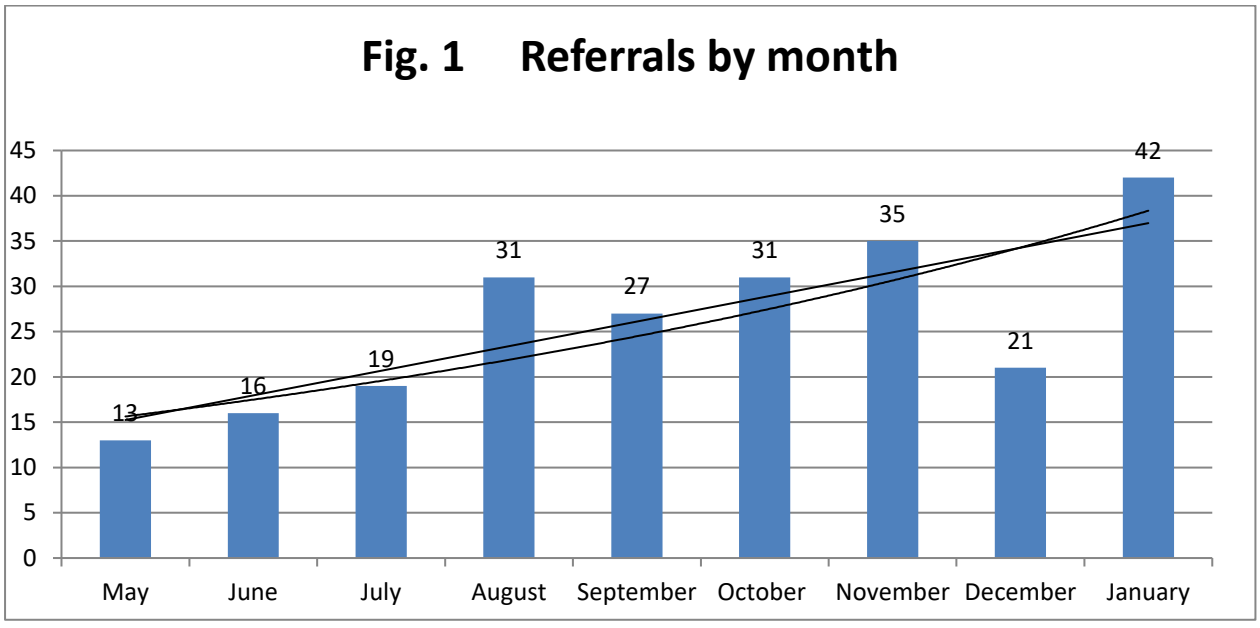
Reflecting on the lower than anticipated number of referrals from the PRST team in May and June, a further round of discussions and feedback sessions with patients and referrers was undertaken in July 2018 and based on feedback from these sessions the following changes were agreed:

1. Placing assessment for practical support at the end of the clinical assessment was problematic because at that point the patient is often tired and no longer receptive to additional information.

2. The *Advice on Prescription* adviser should talk directly to patients in small groups and offer a face-to-face service following referral by health staff.

| Fig. 2 Source of referrals | Referrers | | |
|---|---|---|---|
| 1 | Community Rehabilitation (Breathe) | 162 | 69% |
| 2 | Community Respiratory Nurse team | 31 | 13% |
| 3 | COPD Nurses RLH | 42 | 18% |
| | | 235 | 100% |

Active and ongoing service promotion within the Community Rehabilitation team, COPD respiratory unit of The Royal Liverpool Hospital, the Heart Failure Nurse Team at Arundel House and the Community respiratory Team based in Croxteth Community health proved effective and referrals to AoP increased steadily from August 2018.




## Impact of Intervention

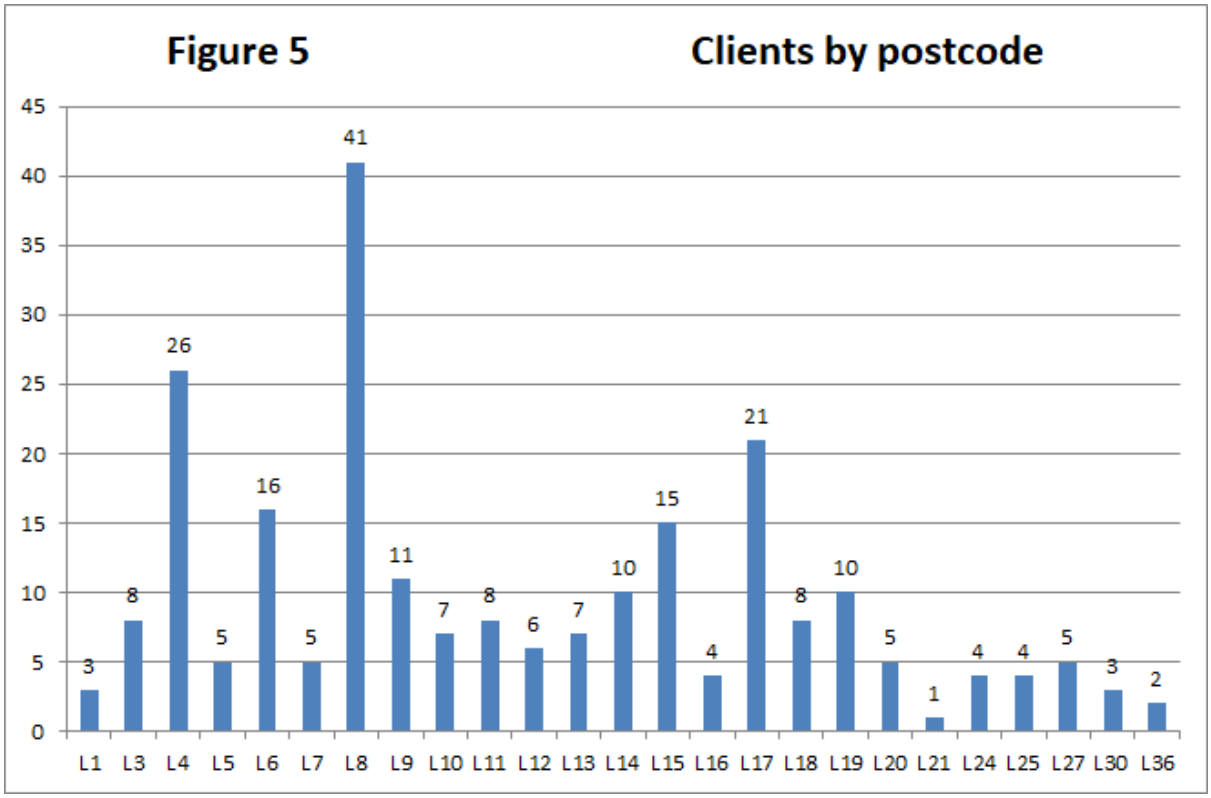
A significant proportion of the people referred to this service have profiles that show markers of significant social and economic disadvantage. Prior to intervention over 44.5% had a monthly income of less than £800, and following the practical advice and support intervention, this number reduced to 24.6% (excluding housing costs).

As a result of this intervention there has been a collective income maximisation of £676,319 and so for the patients referred there has been an average increase in household income of £2,877, with an average debts of £346 managed.

> ***"THE ONE THING THAT ALL REFERRED PATIENTS HAVE IN COMMON IS DIFFICULTY HEATING THEIR HOME S THROUGHOUT THE WINTER MONTHS"***
>
> *REBECKAH DEMPSTER - CASEWORKER*

| **Fig. 3**<br><br>**Monthly income £s*** | **Prior to intervention** | **Following** |
|---|---|---|
| under 400 | 6.6% | 3.7% |
| 400-599 | 13.2% | 4.9% |
| 600-799 | 24.7% | 17.0% |
| 800-999 | 12.3% | 16.1% |
| 1000-1499 | 38.3% | 44.3% |
| 1500-1999 | 2.3% | 10.1% |
| 2000-2499 | 2.6% | 2.7% |
| 2500-2999 | 0.0% | 1.2% |
| Over 3000 | 0.0% | 0.0% |

| **Fig. 4** | **Monthly Income Maximisation 01/05/2018 to 31/01/2019** | | |
|---|---|---|---|
| | AoP3 Number of patients assisted by this intervention | AoP13 Additional annual household income secured as a result of this intervention | AoP14 Amount of household debt reduced as a result of this intervention |
| April | 0 | 0 | 0 |
| May | 13 | 80,856 | 3,400 |
| June | 16 | 55,572 | 600 |
| July | 19 | 68,442 | 1,563 |
| August | 31 | 109,904 | 18,394 |
| September | 27 | 79,686 | 12,470 |
| October | 31 | 63,757 | 5,199 |
| November | 35 | 62,612 | 21,173 |
| December | 21 | 52,690 | 12,750 |
| January | 42 | 102,800 | 11,477 |
| To Date | 235 | 676,319 | 81,463 |




# Learning

## Development of Trusted Partners

Experience gained with the core *Advice on Prescription* (GP referral programme) has shown us that it takes time to develop awareness of a service and that a continual promotion of a service is required to successfully integrate the service into the health professionals' daily practice. Feedback from referrers state that it was helpful to have one dedicated and named adviser/support worker – Rebeckah, who they could develop a relationship with and who they knew would contact their patients in good time.

## Who are the patients being referred and what is important to them?

> *'For the purposes of this pilot, I have been taking referrals from services that are working with patients who have different levels of need, for example, patients referred by the Community Rehabilitation team have been older, more likely to be either long term unemployed or retired, more likely to live alone and be living on a fixed and limited incomes. Patients referred by Community Respiratory Nurse Team were often younger in age but living with high levels of disadvantage and privation, and patients referred by the CODP Nurses in the Royal Liverpool hospital although often employed, were likely to be in low paid, insecure employment and struggling to meet the costs of prescriptions.* Rebeckah Dempster, adviser and caseworker for the test and learn project

Patients referred to this service reported high levels of anxiety and isolation; it is common for people to report feeling 'fed up being stuck in the house', afraid to go out into the fresh air, feeling lonely and unable to do the things that used to make them happy, such as visiting family and friends, walking in the park, light exercise, meeting new people etc.

Many patients referred to the service have many other health conditions; typically, depression/anxiety, arthritis and many have a diagnosis of cancer. Feedback from service users stresses reduced anxiety and increased wellbeing due to worrying less about money and feeling more involved in their families/communities. This quotation from a service user highlights the potential:

> "*My breathing problems meant that I couldn't keep on working, but after coming out of work, I was having problems finding out what benefits I may be able to claim and money was really tight. After trying to sort it out myself for a long time, I was referred to [the respiratory CAB advisor] by the respiratory nurse and she was a great help. She did a fantastic job and now I am not worrying about money and I feel so much better*." Patient

Clinical staff reports that they see the benefits for patients even at the early stage of this project. As a result referrals increased each month. The service has adjusted the delivery model in response to feedback from staff, opening up referral routes to additional services, being more flexible and tailored to the individual group needs on the day but still covering health and benefits and debt plus ways to maximise income. This quotation from one of the Advanced Nurse Practioner illustrates how the service is valued by staff

> "*The process for us has been so easy and for that I thank you. A simple phone call to [the respiratory CAB advisor] makes our job so much easier! We are so happy to have this service available to support our patients*" Pam Jones, Advanced Nurse Practitioner, Liverpool Community Respiratory Team

The informal chats that the *Advice on Prescription* staff have with groups of patients highlight the value of maximising household income as a means of maintaining health. Money management and

effective budgeting to ensure that there is enough money to cover the costs of heating and eating at least one hot, nutritious meal a day. Great emphasis is also placed on providing income maximisation support for referred patients' carers and service promotion leaflets are given to patients who want to include their carers in the service. Groups are also encouraged to discuss housing aids and adaptations with a view to encouraging mobility and confidence indoors.

> *"The feedback I have received from patients', relatives and staff is that the service is amazing and very supportive. Can I also add my thanks to the team for the wonderful service that you are providing it is extremely beneficial to a large number of my patients and I really appreciate the work that you and the team do".*
> Tracy Perry, Respiratory/COPD Clinical Nurse Specialist

## Ways to Wellbeing and Social Prescribing

The importance of a wider health and wellbeing offer was noted by staff and by patients, and this appears to be an area for further development. Patients who received the practical advice and support of the *Advice on Prescription* were also offered the support of a Link Worker (a more recent addition to the Citizens Advice on Prescription team). Physical exercise, being outdoors, having access to some creative and social interaction was appreciated. For many patients who attend the weekly Breathe Programme[1] meetings in the community settings provide support, friendship and a sense of community which many report as having been absent from their lives for many years.

## In-work and Prescription Poverty

This test and learn pilot suggests that in-work and prescription poverty are growing problems for many patients. Difficulties for all referred patients linked to fuel poverty which multiple negative consequences include but are not limited to being:

1. Unable to maintain healthy temperature in their homes
2. Unable to eat at least one hot nutritious meal per day due to not having enough money each day for food or fuel to cook the meal

High levels of social isolation, loneliness, low levels of physical inactivity because of respiratory problems, appear to increase feelings of isolation and low mood within these patient groups.

> *"When it's cold I can't go out and I am too ashamed to invite anyone into my house because it's cold and who would want to sit in the cold?"*Patient

Many of the patients referred by the nursing teams are in full-time work and for those who are in low paid employment the costs of prescriptions is often too much to bear and so many are going without essential medications. Patients and referrers reported incidences of patients making choices between medications (inhalers) and food or fuel. Some patients report sharing inhalers, even drying out contaminated inhalers: one patient's inhaler became contaminated after an accident, and unable to

replace it, the patient continued to use the inhaler, until after a few days they required admittance to hospital with a serious chest infection. Nursing staff in the hospitals were keen to emphasis how fear of job loss often lead to some patients going to work when they were too ill to do so and feedback from discussions with referrers showed justification for using concern over the cost of medications as a marker for a wider discussion about income-maximisation and a referral to the *Advice on Prescription* service. Based on this feedback the *Advice on Prescription* team developed a promotion pack (distributed across all referral points) with information on the benefits of HC1[ii] forms and how to access them.

### Winter pressures

Because the pilot ran from May 2018 to early January 2019 tour data does not monitor the impact of winter pressures on the target patient groups. Feedback from referrers was that activity would increase as winter temperatures reduced and adversely impact existing health conditions. Winter pressures cause problems that require practical support, particularly in relation to keeping homes consistently warm and ensuring sufficient income to buy nutritious ingredients and sufficient fuel to be able to cook it.

### Case Study Three

Another patient referred is currently receiving assistance in relation to welfare benefit application but reported feeling isolated and unhappy, AoP Link Worker developed personalised wellbeing plan with patient who was then accompanied to a local wellbeing centre and is now engaged in counselling, massage and mindfulness.

## Conclusion

The project has been valued by services and participants, and Liverpool CCG and Citizen's Advice South Liverpool are working together to explore ways of sustaining it, based on the summary points below:

- There are considerable levels of unmet need in patients using respiratory services, particularly relating to prescription, fuel and food poverty. Most patients supported by the service did not know that they were entitled to financial and practical support.
- Referrers report improved outcomes for their patients.
- *Advice on Prescription* is a community-based service and has been effective in developing relationships with acute services through a process of in-reach, liaison and awareness-raising.

- As a result of this model, patients who were referred into *Advice on Prescription* were connected back to support and activities in their local communities. This is an important dimension and would like to explore this further.
- Clinical nurse specialists and advanced nurse practitioners are important groups of staff, and were key to making this community in-reach model more effective. Staff in respiratory services were pleased to work with *Advice on Prescription* in order to open up routes to health and wellbeing support for their patients.

[i] The Breathe Programme is a flexible programme of exercise and education for patients with chronic lung conditions such as COPD (Chronic Obstructive Pulmonary Disease), bronchiectasis, fibrosis, breathing pattern disorders and asthma. USING exercise and education to help patients, manage their disease, reduce dependence on hospital facilities and work out ways of living the best possible life. It is an 8-week course provided in community settings across the city. Once completed the patient is discharged from the programme.

Over 40 discharged Breathe Programme patients are now working with a dedicated Link Worker to develop a long term personalised plan, and the most popular wellbeing services take up are: yoga, local history digital photography and confidence building support groups.

[ii] NHS application forms that provide access to forms which provide access to help with prescription cost for patients with low incomes.

## Acknowledgements

Caryn Matthews, Chief Executive Office of Citizens Advice South Liverpool 1997 -2018, now retired, for her tireless efforts to raise awareness of the links between poverty and ill health and the need for practical advice and support for those who are furthest away from services.

Clare Mahoney, Andy Kerr, Janet Bliss from Liverpool CCG, whose vision and commitment helped shape this endeavour.

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Pam Jones, Community Respiratory Team

Tracey Perry and Sarah Hopkinson from Community Respiratory Team based in Liverpool Royal University Hospital (RLUH)