**Final report**

March 2018

# Innovating for Improvement

## Psycho-social interventions to improve self-management of long-term conditions

First Contact Clinical

The Health Foundation

## About the project

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**Project title:**

Psycho-social interventions to improve self-management of long-term conditions

**Lead organisation:**

First Contact Clinical

**Partner organisation(s):**

NHS South Tyneside Clinical Commissioning Group

**Project lead(s):**

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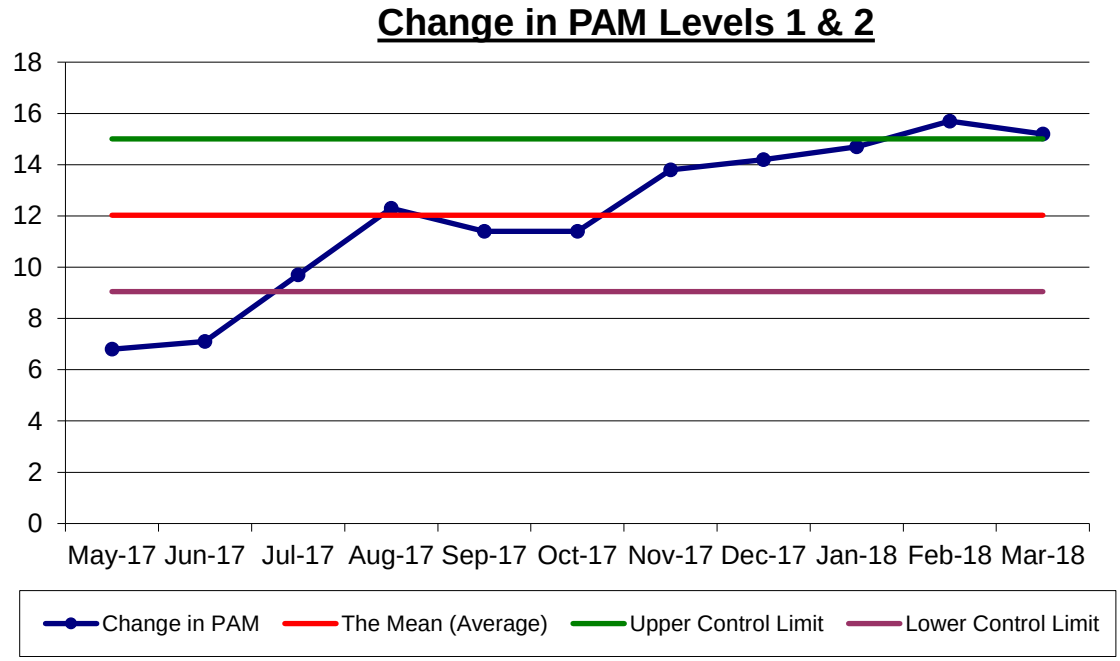
## Part 1: Abstract


The care for patients with long term conditions is predominantly delivered by medical and other clinical staff and whose focus is primarily on the physical consequences of the “illness”.

Our intervention offers patients stepped care approaches to psycho-social interventions in primary care. Patients entered our project as part of their long-term condition review or following a new diagnosis in primary care. The intervention is based on their ‘Patient Activation Measure’ score (PAM; an indicator of their ability to self-care). Those with the lowest PAM scores are offered the most intensive intervention.

Our proposal was informed by our work with people with addictions. Addiction has a relapsing remitting course and is frequently referred to as a long term condition. The combination of psychosocial interventions (delivered by a multi-disciplinary team of trained practitioners and people with a lived experience) with evidence based clinical care (delivered by medical and other clinical staff) is considered “normal” best practice in this particular long term condition. We were struck that this is not the case with other long term conditions where care is predominantly delivered by medical and other clinical staff and whose focus is primarily on the physical consequences of the “illness”.

We aimed to increase PAM scores for those with lowest initial ratings after an agreed intervention time and at regular follow-up intervals.




In addition to seeing an increase in PAM scores for those with the lowest initial ratings; we anticipated that primary care would see a reduction in unplanned visits

for long-term condition-related problems. The data shows that on average there is a reduction of 6.7 attendances per patient.

The greatest risk we highlighted was the current primary care environment: the increasing pressures the teams face to deliver more for less. In reality the practice teams involved in the project made a positive impact on the project. Their enthusiasm to change pathways in order to integrate the intervention enabled us to implement and test out our theory.

Our project will be sustained beyond the funding period due to securing a further 12 months of grant funding. We have secured funding to spread the intervention into a further 3 practices. We have secured funding to spread the intervention to another long term condition: patients who have been diagnosed with Diabetes within the last 12 months, but who have not attended structured education.

We are actively working with commissioners to secure mainstream funding in order that the intervention can be offered across the borough to all patients with a long term condition.

## Part 2: Progress and outcomes

**Intervention:**

Patients enter our project as part of their long-term condition review or following a new diagnosis in primary care. The intervention is based on their 'Patient Activation Measure' score (PAM; an indicator of their ability to self-care).

Patients are offered stepped care approaches to psycho-social interventions, ensuring those with the lowest PAM scores are offered the most intensive intervention. For example, a patient with a level 1 score are offered a programme of 5-6 face to face sessions with a Trainee Health Psychologist; a level 2 patient has sessions with a Self-Care Practitioner; a level 3 patient is provided with information from a Social Prescribing Navigator; and a level 4 patient has access to a mutual aid group.

**Innovation:**

Our proposal was informed by our work with people with addictions. People with addictions are able to access clinical care, psycho-social interventions and mutual aid in primary care settings. The level of intervention is stepped up and down following clinical review and objective assessment of people's physical and psychological health needs. The goal is Recovery which is defined as remission from the symptoms of addiction, improvements in global health and wellbeing and increased citizenship (White: ROMM Paper).

Addiction has a relapsing remitting course and is frequently referred to as a long term condition. The combination of psychosocial interventions (delivered by a multi-disciplinary team of trained practitioners and people with a lived experience) with evidence based clinical care (delivered by medical and other clinical staff) is considered "normal" best practice in this particular long term condition. We were struck that this is not the case with other long term conditions where care is predominantly delivered by medical and other clinical staff and whose focus is primarily on the physical consequences of the "illness".

We are aware that disability with long term conditions is often independent of disease burden yet despite this the psychological health needs of people with long term conditions are rarely acknowledged (Kings Fund Paper: Integrating Physical and Psychological Health) until they become a diagnosis in their own right. From our work with people with addictions we are aware that a one size fits all approach to care does not work. Within our service we offer a proportionate response to those with the highest need. We step up the care offered to the most complex and step it down when they no longer require it following objective review of progress.

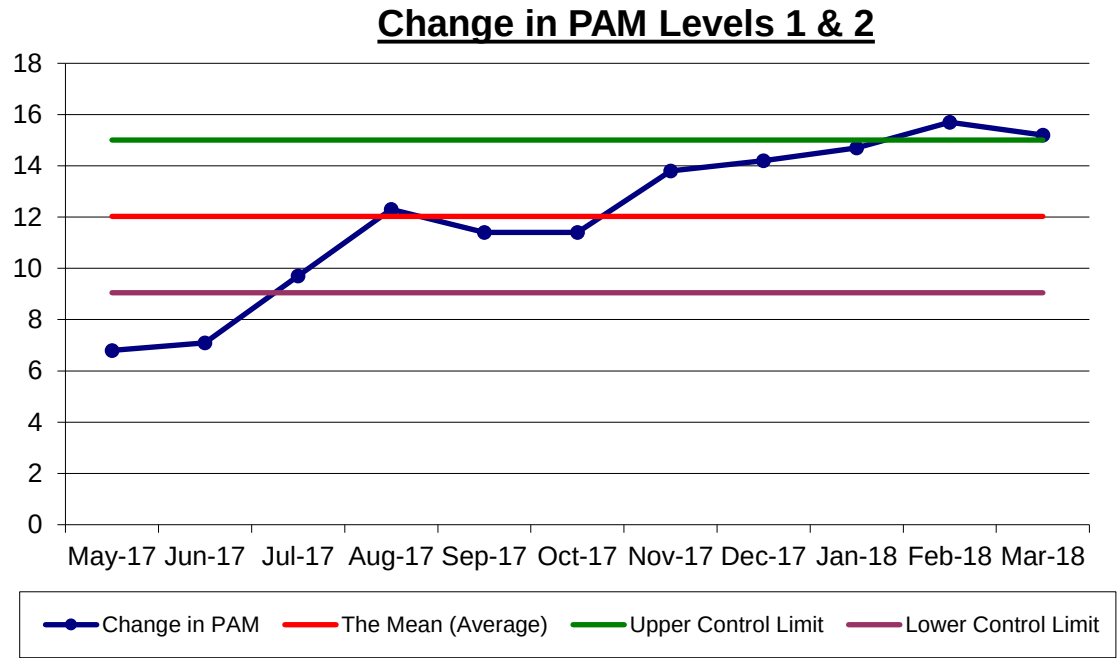
Evidence suggests that when considering predictors of effective self-care people with the lowest level of activation as measured on the PAM are the least able and require a different level of support than those who start with a higher level (Kings

Fund Paper: Exploring Activation). They require a proportionate response.

When considering the transferability of our model into other Long Term Conditions our proposal was influenced by the work seen in the Dutch healthcare system. As Derksen (2009) reports, integrating Primary Care Psychologists into the Dutch healthcare system allows the patient to access service quickly and reaffirms our understanding and current addictions work that empowering clients and remaining integrated in the community is vital. A Primary care psychology service would enable us to spread this learning into Long-term conditions and grow the community and self-care spirit. Other attempts at integrating psychology services in some form into the primary care pathways have shown improvements, not only in patient wellbeing and physical functioning, but also in the number of healthcare provider visits and the use of pain medications (Hoffman et al., 2007). We also know that these condition specific interventions have worked but more is needed to allow for tailored multi-disciplinary care (Elder & Silvers, 2009) and a stepped care approach may allow us to improve the management of chronic conditions in primary care (Beaglehole et al., 2008).

**Outcomes:**

We aimed to increase PAM scores for those with lowest initial ratings after an agreed intervention time and at regular follow-up intervals.



We also developed a Mutual Aid Group, a community based asset where people with LTCs can support each other to self-help.

**Patient Feedback:**

*"I was completely blown away with the support you were offering me and my wife after meeting you in clinic, really pleased with you both and this service is a wonderful idea."*

*"It's amazing how much you want to help me and how kind and supportive you both are when you talk. I was really looking forward to our chat today."*

*"It's a great feeling knowing that someone cares about us and will offer us great advice."*

**Practice Team Feedback:**

*"We've noticed a massive difference since the team started working at our surgery."* GP

*"[Patient] is a completely changed person from the one I sent through. They've made some big changes and the improvement to their confidence is visible."* Practice Nurse

Appendix 1 includes some resources developed to support the project.

## Part 3: Cost impact

**Funding:**

We have been able to deliver the intervention in two practices with the funding. We have secured further funding through a Pioneer route to continue the project for a further 12 months.

We have secured funding to spread the intervention into a further 3 practices by securing some monies through the Cancer Network. The target group for this project is still patients with COPD, and therefore at high risk of developing cancer.

We have secured funding to target patients who have been diagnosed with Diabetes within the last 12 months, but who have not attended structured education.

We are actively working with commissioners to secure mainstream funding in order that the intervention can be offered across the borough to all patients with a long term condition.

**Cost Impact:**

It is anticipated that in addition to seeing an increase in PAM scores for those with the lowest initial ratings; that primary care would see a reduction in unplanned visits for long-term condition-related problems; and that secondary care would see fewer unplanned emergency care visits from patients engaged with the project.

We did not commission an external financial evaluation of our project. We did access health intelligence software in order to estimate using a sample of data the financial impact to both primary and secondary care.

After 100 patients had completed a second PAM we randomly selected approximately 1/3 to compare primary care attendances before and after their intervention began. We continued to follow these patients to compare their primary care usage the 9 months before their intervention began and 9 months after.

The data shows that on average the sample group had 10 primary care attendances before their intervention began and this reduced to an average of 3.3 attendances for the 9 months following. This equates to a reduction of 6.7 attendances per patient.

If we extrapolate this up for the number of referrals seen over the lifespan of the project we would have save 2,747 attendances. If extrapolated for patients living in South Tyneside on the COPD register this would equate to 38,431 attendances. This would equate to 6,405 hours of primary care time.

We have not been able to measure the impact on secondary care visits or costs. The challenges of understanding the impact on secondary care costs have been:

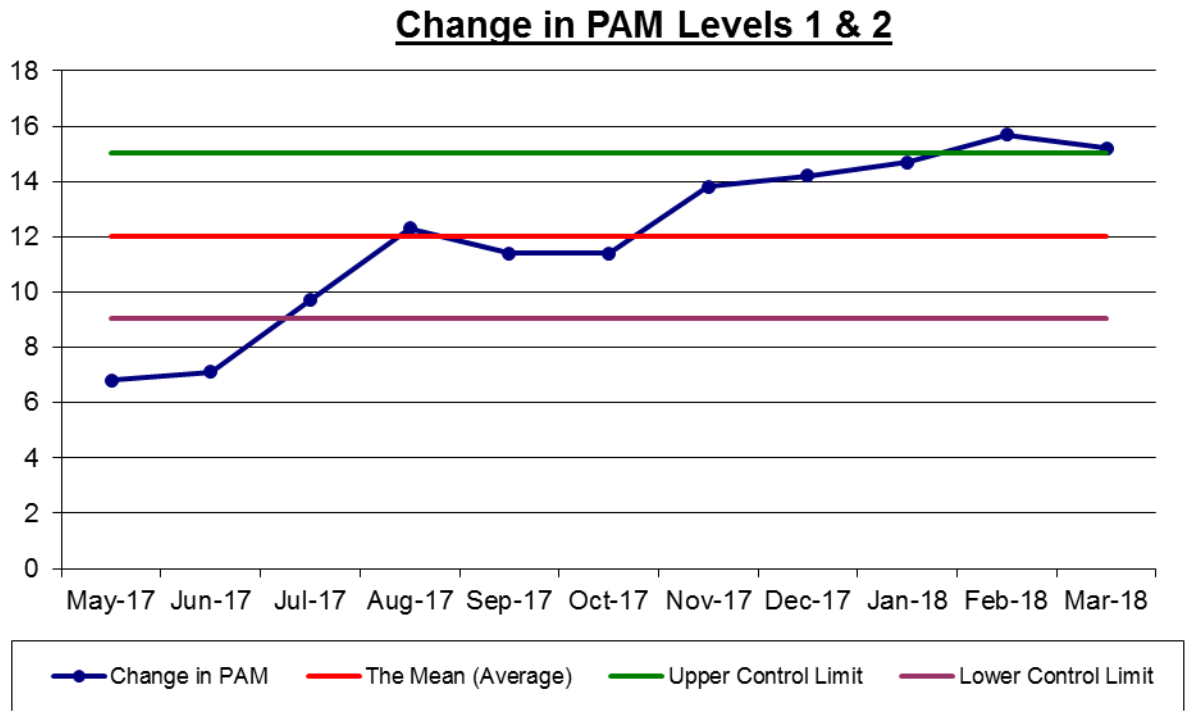
- The length of time taken to gain access to the information system. This involved honorary contracts and a lot of following up the request.
- Initial access did not provide access to relevant datasets.
- We then found that the secondary dataset the system gave us access to is for fixed periods and cannot be manipulated so impossible to retrospectively understand the impact at an individual patient level.

We included staff costs only in our budget forecasts. We accurately estimated the implementation costs in respect of staff time, but did not plan for the Management Information System development costs. Moving forward we will be looking to fully include all associated costs involved in the delivery of a community based service.

## Part 4: Learning from your project

**Reflections:**

Overall we did achieve what we hoped to achieve at the start of the project. We aimed to increase PAM scores for those with lowest initial ratings after an agreed intervention time and at regular follow-up intervals.




We also hoped to see a reduction in unplanned visits for long-term condition-related problems in primary care. Our sample data shows that on average the sample group had 10 primary care attendances before their intervention began and this reduced to an average of 3.3 attendances for the 9 months following. This equates to a reduction of 6.7 attendances per patient. We had predicted the possibility of an increase in attendances following increasing activation, this was not seen as we measured the difference at 3 months, 6 months and 9 months following the start of the intervention. Each milestone showed on average a reduction in attendances.

Another bit of reflection is that measuring the impact on primary care is time consuming.

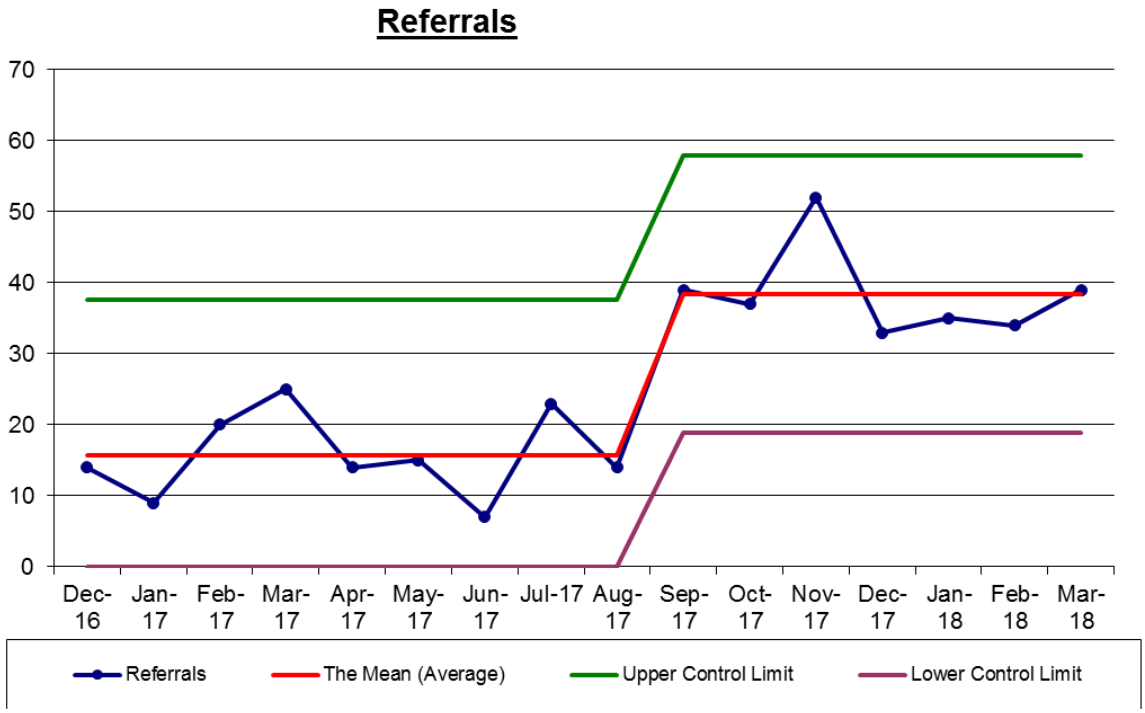
We haven't been able to show if we have reduced secondary care utilisation.

Evidence suggested that 26% of the patients would be PAM level 1 or 2. At some stages the level of 1's and 2's had not been as high as anticipated which led us to question if integrating into the annual review pathways was allowing us the opportunity to engage the less activated patients. This was one of the risks we highlighted. It is an area we will continue to measure. However, in terms of active

caseload latest figures show we have seen 62%.

Our biggest reflection was in June when the data showed that we were actually spending more time with the activated patients. By the very nature of the fact they were activated they were easier to engage, more willing or more demanding. The team had to consciously ensure that the intensity of the intervention was weighted towards the less activated patients.

We had anticipated referrals to be circa 800 during the 12 month period, but saw only 410 referrals. The figures were based on the COPD registers numbers, however not all of the patients attended an annual review or a review on the days of the integrated clinics. We also saw an impact on the referrals when the LTC nurse was on leave.




We planned for the interventions to be weekly over 6 to weeks. In reality, some patients need time between sessions to achieve their goals or space for social factors to be managed. The time between the sessions is patient led.

For the majority of the project the team have worked in a role based manner, but recent reflections are that a more practice based model would support improvement integration into practice teams, greater responsibility for outcomes, be flexible to the patients' needs and support the (primary care) system needs.

**Enablers:**

The greatest risk we highlighted was the current primary care environment: the increasing pressures the teams face to deliver more for less. In reality the practice

teams involved in the project made a positive impact on the project. Their enthusiasm to change pathways in order to integrate the intervention enabled us to implement and test out our theory.

We ensured staff buy-in by regularly attending practice meetings and sharing patient stories. The practice supported patient engagement by notifying patients of the new pathway in their invitation letters. They also located the room for our staff beside the nurse's room to further support engagement.

We introduced a monthly newsletter over the last 6 months in order to increase the understanding and awareness of the service and the impact.

Nationally there is a bigger focus on self-care, increased wellbeing and community based approaches. This has increased interest in our project.

The patients themselves have also been big enablers. We supported 3 patients to graduate from our volunteer training programme. They have been co-facilitating the mutual aid group and one is being supported to start a second group which he will facilitate.

**Challenges:**

Our biggest challenge has been and continues to be that we have not been able to measure the impact on secondary care visits or costs. The challenges of understanding the impact on secondary care costs have been:

- The length of time taken to gain access to the information system. This involved honorary contracts and a lot of following up the request.
- Initial access did not provide access to relevant datasets.
- We then found that the secondary dataset the system gave us access to is for fixed periods and cannot be manipulated so impossible to retrospectively understand the impact at an individual patient level.

This is an important measure in being able to increase confidence in commissioners that the intervention can release cost from the system.

**Patient Feedback:**

*"I was completely blown away with the support you were offering me and my wife after meeting you in clinic, really pleased with you both and this service is a wonderful idea."*

*"It's amazing how much you want to help me and how kind and supportive you both are when you talk. I was really looking forward to our chat today."*

*"It's a great feeling knowing that someone cares about us and will offer us great advice."*

**Stakeholder Feedback:**

*"We've noticed a massive difference since the team started working at our surgery."* GP

*"[Patient] is a completely changed person from the one I sent through. They've made some big changes and the improvement to their confidence is visible."* Practice Nurse

**Team Learning:**

The project has allowed the team to experience taking an idea and implementing / mobilising as a service. The biggest achievement is listening to the patient stores: the impact that the intervention has had on the 'causes of the causes' of the risks.

We are more aware that the system is very much a medical model. Trying to liaise between primary, secondary and social care systems is quite challenging. In some instances it feels that no-one is taking responsibility.

We now realise that some measures may seem simple, but are actually very difficult to monitor. Systems do not speak to one another and a dataset surrounding the patient is not available.

Integration from key staff makes life so much easier, we believe this was because we included them in the design process. Systems and processes that are co-designed are more readily adopted.

We continue to work with the different stakeholders to understand what measurements they are most interested in.

## Part 5: Sustainability and spread

**Funding:**

Our project will be sustained beyond the funding period due to securing a further 12 months of grant funding. We have secured funding to spread the intervention into a further 3 practices. We have secured funding to spread the intervention to another long term condition: patients who have been diagnosed with Diabetes within the last 12 months, but who have not attended structured education.

**Sustainability:**

We are actively working with commissioners to secure mainstream funding in order that the intervention can be offered across the borough to all patients with a long term condition.

Our proposal was informed by our work with people with addictions. People with addictions are able to access clinical care, psycho-social interventions and mutual aid in primary care settings. The level of intervention is stepped up and down following clinical review and objective assessment of people's physical and psychological health needs. Therefore, we feel our work has demonstrated that the model can be replicated in other areas of the health and social care system.

The strength of our organisation is the expertise of primary care and psychosocial interventions.

**Interest:**

We have had a lot of interest from practices across the borough. We have selected practices based on deprivation in order that we can make a difference to those less activated.

The project and interim findings have been shared at a post graduate conference in Staffordshire University and some local educational meetings.

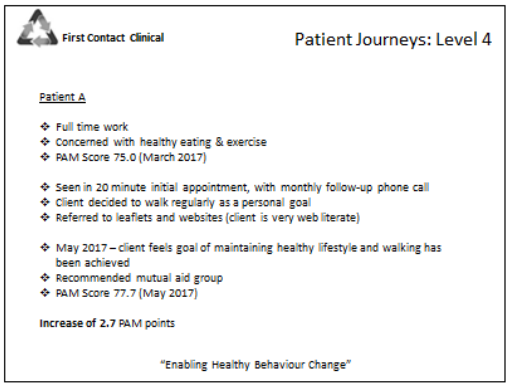
**Change as a result of implementation:**

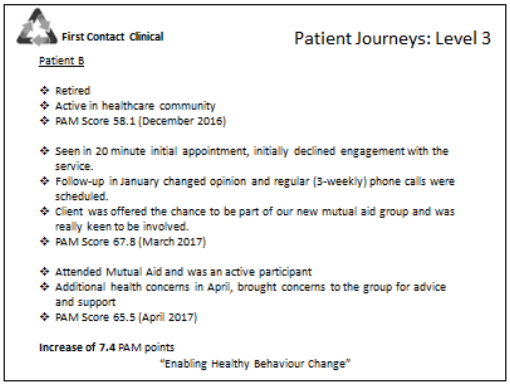
Whilst the intervention hasn't necessarily changed the methods in which we use to engage those that would benefit most has and will continue to change. Our biggest learning is that the most activated will attend planned care, yet we get most success engaging with people who use unplanned care instead of planned care.

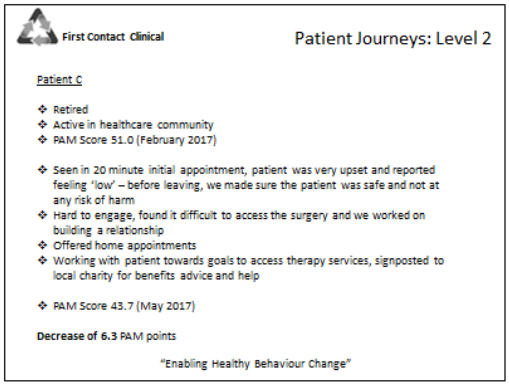
## Appendix 1: Resources and appendices

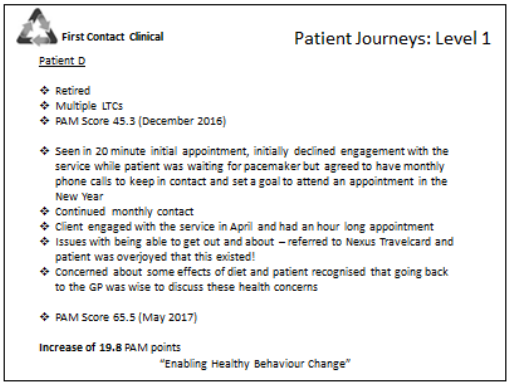
**Mutual Aid Flyer:**


**Early Case Studies:**




## Where do we refer?

- GP Practice
- Pharmacists
- Nexus Services
- Adult Social Care
- Pulmonary Rehabilitation
- Smoking Cessation
- Mental Health Services
- Mutual Aid
- The Relative Project
- Substance Misuse Services
- Mortimer Community Network
- Happy at Home
- Age UK
- WHIST
- Warmzone
- Miners' Association
- BLF – BreatheEasy
- Greggs' Foundation
- South Tyneside College
- Combined Touch
- Arts for Wellbeing