

Evaluation of the Patient Leaders Programme 2015-2016

The Patient Leaders project was launched in April 2014. The aim was to provide a programme of training and developmental support to a small group of Tower Hamlets residents to enable them to take on leadership roles in local health and social care context. This report presents a review of the impact of the programme upon the second cohort of participants.

At the end of the second full year of the programme each Patient Leader was asked to participate in the evaluation by completing a questionnaire, participating in an evaluation interview and completing a report that presented outcomes from their work. Additionally, feedback on impact was sought from staff involved in the programme from Tower Hamlets Clinical Commissioning Group (CCG) and Healthwatch Tower Hamlets. The team at Social Action for Health have also been reviewing their own understanding of the Patient Leaders and using this knowledge to understand the difference that they have been able to make.

1. Outputs of the programme

All 14 participants have attended the training sessions and the coaching sessions. However 4 participants couldn't continue to complete the program as they were looking for employment and had to leave the program.

Table 1. Demography of participants from Cohort 2

Ethnicity	Post code	Gender	Age range
Bengali – 7	E1 – 8	Female – 10	20-29 yrs – 1
Black British – 2	E2 – 5	Male – 4	30-45 yrs – 8
Mauritius – 3	E3 – 1		46-55 yrs – 5
White British – 2			

Together the Patient Leaders were involved in excess of 600 hours of activity relating to health and social care engagement during the course of the year. The scope of these activities ranged considerably from attendance at partnership group meetings, sitting on consultation panels, attending briefing and training sessions, peer mentoring activities and one-to-one meetings with commissioners, health professionals, community members, experts and decisions makers.

Below is a summary of the findings from the questionnaires, interviews and individual reports.

The Patient Leaders remain actively involved in taking on leadership roles in health and social care in Tower Hamlets.

2. Outcomes of programme: Changes reported by Patient Leaders

The Patient Leaders Programme is a series of coaching and training sessions, and engagement activities intended to build leadership skills in participants. The structure of the programme provides a platform for Patient Leaders to meet people who share similar ideas and a passion to create change in the Tower Hamlets community. We recognise varying levels of health care knowledge and leadership experience based on educational background or past employment

opportunities. However, with a focus on agency, awareness, and association, Patient Leaders can gain personal and professional development to take on leadership roles in their community. A Patient Leader expressed, *“I now have a better understanding of the leadership concept, what it entails to be a good and productive leader; both in theory and practice.”*

Some of the Patient Leaders commented on the coaching sessions as an integral part of their training. These one-on-one sessions enabled both Patient Leaders and project managers to get to know each other better and to discuss how Patient Leaders could be supported in their endeavors.

According to two Patient Leaders, the coaching sessions:

“...helped me open up a conversation with a healthcare professional whereas before I would not have the confidence to do so.”

“...identified my potential and set personal goals. They [Nurun and Jane] both championed me with words of encouragement, which gave my morale a boost.”

Another Patient Leader stated, *“The support from SAFH was a back bone. It gives you a title, which allows you to engage in the NHS hierarchy. SAFH is a point of reference and gives legitimacy to your voice and an extra identity.”*

Similar to the evaluation reports from Cohort 1, the evaluation reports from Cohort 2 suggest a range of changes amongst Patient Leaders (PLs) that can be summarised as follows:

- Personal skills & abilities
- Knowledge & awareness
- Networking

2.1 Personal skills & abilities

The evaluation reports show an increased sense of agency and refinement of interpersonal skills in Patient Leaders. They have increased their confidence and self-esteem by interacting with each other and others in their community.

“I have become more independent.”

“I have also learnt to speak up for myself.”

“I feel that I have learned a great deal about myself and how others perceive me.”

“It [The programme] enabled me to broaden my vision, helped me raise the expectations I have of myself, assisted me in exploring my potential.”

Training sessions on active listening and effective communication taught PLs the four parts of speech and the importance of ‘I’ statements. They have become more aware of the value of their voices and providing relevant input in conversations and at engagement activities. They are making a conscious effort to formulate their sentences on views on issues. Additionally, reflection activities provided insight to the practical applications of training in their projects and everyday life. *“It allowed me to actively make use of the material given to me and applying the theories to real life situations.”*

Patient Leaders have also learnt the value of working together as a team to empower others. One PL commented, *“I am now able to liaise with others to seek support and offer support.”*

PLs are empowered to take personal areas of interest such as disability rights, mental health, and parenting to be advocates and a voice for those who cannot speak up for themselves. They provide perspective to health care professionals and stakeholders to support others in similar circumstances. Training on dealing with messes has helped PLs overcome difficulties and familial circumstances, and put them in the past to see health care in a new way.

Two PLs stated,

“I have been able to influence and set an example that disabled people have a voice that a lot of disabled people want to make an impact on the health care they receive.”

“I believe the PL course has shown me a way to move forward. It has shown me a way to put my experiences into perspective, also shown me a positive side to my experience.”

2.2 Knowledge & awareness

The Patient Leaders have gained knowledge in a number of different ways, however a key area of change is increased knowledge in local NHS services, how decisions are made and how to influence these decisions. Some PLs have expressed their impression of NHS before going through the programme.

“...the NHS is very hidden, it’s another world.”

“All my life I had used health care services yet didn’t have a clue what was going on behind the scenes.”

As a result of training sessions and engagement activities, Patient Leaders have gained insight into how NHS England operates, prioritises and spends funds on services. Some members of Cohort 2 were given a virtual tour of NHS and its organisations, which allowed them to directly access the part of the health care system in which they are interested in leading change. Additionally, Big Conversation and Seeing the Bigger Picture workshop trainings allowed PL to learn about the variety of services NHS offers and to have face-to-face contact with CCG commissioners and other stakeholders. At meetings with stakeholders, Patient Leaders are representing Tower Hamlets residents and they discuss issues of community involvement, language barriers, and lack of confidence that may prevent others in the community from approaching NHS.

“The wider knowledge that I have gained, about the NHS has enabled me to advise members of the public, with confidence; directing to appropriate services and signposting, or simply listening.”

Not only are Patient Leaders using increased knowledge and awareness to make change in health care but also in their personal lives. Several PLs have commented on how different elements of training and engagement activities have been integrated into everyday practices.

“Learning about difficulties and messes, I have learnt the techniques behind tackling changes, whether in my personal life or in healthcare.”

“Going to engagements with an emphasis on good living and health eating, encouraged me to make changes to my own lifestyle and diet.”

“I personally have felt better for making changes, and I don’t think I would’ve considered making them, if I hadn’t become more aware of health problems affecting Tower Hamlets residents, but I also feel like an advocate for better living.”

“...improved the way I speak at home, especially with my children, before we would all try to talk over each other, trying to get a word in edge ways. Now I encourage each of us to stop, wait our turn, and listen to what the other person has to say.

2.3 Networking

The programme takes a social approach to fostering change in the community by creating cohorts to serve as support systems for PLs. *“Change is a dynamic process where building relationships and trust play key roles.”* The cohorts are designed by bringing people from diverse backgrounds together to share experiences. PLs are able to see things from a different perspective and try to understand another person’s point of view. They have become more mindful in their interactions with others. One PL expressed:

“I need to be sensitive of ethnicities and how communities are labeled. I live in a diverse neighborhood in the city and I need to know the challenges that the community faces so I can represent their voices to the best of my abilities.”

In addition to building relationships within the cohort, Patient Leaders are conversing with stakeholders in the health care system at engagement activities for project support and training enhancement. These connections help them gain more information about an area of interest as well as opportunities to contribute to services.

“When I had weekly training sessions to go to I felt I could actually have a impact on our community, I was meeting local residents, communicating with the other patient leaders, it feels like you’re creating new networks.”

Patient Leaders continually avail themselves of opportunities to further their personal and professional development through their network. Several PLs are using transferable skills from the programme to stand out as qualified candidates in the workforce.

“I am now considering taking a few courses to equip myself for a better job prospect.”

“I have learnt some invaluable skills that I hope I can bring to future employment or even more voluntary roles.”

3. Impact

The following four areas emerged as areas of impact:

- Influencing provision of local services
- Influencing and shaping commissioning priorities
- Redefining and influencing Patient & Public Involvement locally

- Impression and recognition of Patient Leaders by stakeholders

In addition to these areas of positive difference, we have also identified the ‘negative’ impacts and suggestions for improvement from the programme and report on these separately.

3.1 Influencing provision of local services

The Patient Leader make observations in their community and use knowledge they have learnt in training sessions and engagement activities to create projects. Below are some examples of the projects underway in our community:

- A Patient Leader noticed a surplus of young Bangladeshi women who were on anti-depressant medications. She believed the women could change their situations by adjusting their behaviour and physical activity level rather than relying on medications. After surveying groups of women under 30 years old and over 30 years old, she designed an experiment to take the women off the medication. She provided details of free gym, swimming, English and cooking classes in the community. Women who participated in these activities showed changes in their sadness and moodiness. The activities allowed some to become empowered and enabled to overcome their fear of depression or isolation by engaging with others in their community.
- A Patient Leader was interested in identifying health issues in Tower Hamlets, finding its contributing causes, and offering a solution. She spoke to a variety of individuals including GPs, school nurses, health visitors, and parents and found that asthma was a concern for many. Parents voiced their concerns to the Patient Leader regarding overcrowded housing, lack of hygiene, and minimal open spaces for children to play due to pollution. The PL also found a lack of education among parents, which is a stumbling block to their empowerment and knowledge of health education.
- Similar to the PL above, another Patient Leader was interested in asthma in the community and started the “Asthma Project”. The intention was to create a focus group to work with Tower Hamlets CCG to identify themes and patterns in how parents and GPs are handling asthma in children. Recognising key problematic areas can produce action points to address the health concern and reduce the number of asthmatic cases seen at A&E.
- Another Patient Leader wanted to change the system of making appointments at the GP surgery. After speaking to members of the Tower Hamlets community, she noticed how long it took to make a GP appointment, which resulted in longer queues at A&E. PL spoke with a junior doctor about the situation under the new contract. The junior doctor shared how busy the doctors are and how they already work 7 days a week. The doctors genuinely care about their patients’ safety as well as their own wellbeing. The PL was a liaison and informed community members what she learnt from the junior doctor so they are more educated of the “behind-the-scenes” at the GP surgery.
- PL is working with families with twins/multiple births, or 2 or more children under the age of 5 – a vulnerable sector of the community that has been neglected from social services. She is working with stakeholders to create a system of care packages for these families and assess need on a family basis.

3.2 Influencing and shaping commissioning priorities

- A Patient Leader became involved with an Integrated Personal Commissioning workshop organized by Tower Hamlets CCG. Various health professionals including GP's and mental health, social services, advocacy charities, Patient Leaders and service users were invited to discuss new ways in which care packages were allocated, assessed and funded. The idea was to give disabled residents more independence and control over their own personal budgets and care plans, giving them the freedom to spend the funds on things they actually felt were beneficial to their lives and employ a carer they actually liked and wanted. During the workshop I know I made quite an influence being one of the few wheelchair users, who also received care plans.
- Two Patient Leaders founded a co-production group called Realising Change, after attending the Integrated Personal Commissioning workshop and meeting a representative from Real. This co-production group meets once a month before the CCGs meet for their monthly meeting. The purpose is to discuss the progress of the new care package setup and to get new users to agree on having an independent budget.
- One Patient Leader is a member of the Shadow People's Panel, which is run by Tower Hamlets CCG to engage residents in shaping future services.
- PL created a virtual hub for individuals with long-term medical conditions. The design was previously in existence for clinical use but not universal use that could be accessed from different private establishments. She is currently assisting the marketing sector of Tower Hamlets CCG to develop the database.

3.3 Redefining and influencing Patient & Public Involvement locally

- Patient Leaders are signposting what they have learnt at engagement activities for local residents to learn more. They are able to share the information and connect people to the right resources.
- A Patient Leader joined a school group to discuss everyday issues parents face and work as a team to identify and problems and resolutions.
- Many Patient Leaders attended The Big Conversation Event, which allowed them to voice their opinions and share ideas with others from the community. They were participating in critical and interactive discussions regarding the challenges and issues faced in managing health and social care in Tower Hamlets.
- A Patient Leader had the opportunity to attend Qualitative Research training, which was a four-day course on learning the methods to obtain qualitative data from the community. The course taught the PL how to engage with the community through focus groups and one-on-one interviews.
- A few Patient Leaders completed Enter and View Training, a one-day course that teaches participants how to be a good authorised representative and learn how to assess services. By visiting hospitals and care homes, PLs are able to observe how services are delivered and listen to the concerns of service users. PLs report this information back to the service provider to raise issues for improvement as well as recognise the service given.

- Patient Leader chairs 'Your Say Your Day' events sponsored by C.O.I.N. (Community Options Involvement Network). One event was titled Parity of Esteem, which means one's mental and physical health is valued equally. The event included speakers and workshops that covered the elements of Parity Of Esteem, and the national priority of improving outcomes for individuals with lived experience of mental health. Another event was on Medication and You, which included speakers and workshops that covered mental health treatment information and options, and addressed concerns on effects of drugs on patients.
- PL participated in the Mental Health First Aid Standard Course. This training course run by MHFA England teaches participants how to recognise signs and symptoms of various mental health issues and how to guide others toward appropriate professional help.
- Another PL is the Chair for Tower Hamlets Mental Health Task Group. This group plans projects and workshops addressing various aspects of mental health.
- Patient Leader stood for a seat as a Governor from Tower Hamlets on the East London NHS Foundation Trust Council of Governors as an elected member from 2015-2016.

3.4 Impression and recognition of Patient Leaders by stakeholders

To complete their evaluation reports, Patient Leaders reached out to stakeholders with whom they have been working to comment on their work ethic and contribution to the initiative. Below are testimonies on some of the Patient Leaders.

- *"PL was confident in sharing thoughts and ideas in the workshops we attended. She drew on her own personal experience, which really helped professionals understand a different perspective. PL made a positive contribution to the early development of our IPC programme."*
- *"PL displayed confidence and mutual respect for the people around her and a willingness to listen and understand different perspectives. These invaluable skills are developing her expertise as a patient leader."*
- *"PL dealt with the situation diplomatically and resolved any potential conflict escalating."*
- *"Since the first session, PL started to proactively engage in all conversations as well as actively taking part in group activities and role-plays with her peers, which showed her ability to engage and interact as a good team player."*
- *"PL was an active participant of the session and contributed substantially in relaying her own experiences of local health services and asking relevant questions about the impact of visits on improving health and social care services for local people."*
- *"PL is an outstanding chairperson, since he became the chair of the Mental Health Task Group last year (2015), the operational management of the meetings have improved substantially e.g. he is very assertive in timekeeping the meetings; he ensures that everyone has a voice and provides them the capacity to express themselves; he ensures that no one person dominates the meetings; he summarises key points well and he is good at asking questions and holding commissioners and service providers to account."*

- *“PL has spoken about how the Patient Leaders Programme has benefitted him...all of these personal development traits PL has spoken about has shone out in abundance during his active involvement with Healthwatch Tower Hamlets in the last year.”*

3.5 Negative Impact

The following feedback was taken from the Patient Leaders themselves and the lessons arising, which are being considered as we move into the third year of the programme.

In the report for Cohort 1, “feeling the pressure of time” and “feeling stressed and guilty” were listed as negative outcomes. SAfH and stakeholders committed to an action plan to make a reasonable time commitment for Patient Leaders and adjust the framework to be a less stressful environment. These negative impacts have been addressed and resolved as a result of Cohort 2 evaluation reports.

“...course is delivered in an informal manner.”

“I felt that the course was at times a little less structured as I would have liked but this may be because I am more used to specific agendas, this challenged my unease at being thrown into chaotic situations. I now feel less stressed if I find myself in these situations like a big public meeting – I’m less likely to walk out half way or feel frustrated.”

Group dynamics

In several of the Cohort 2 evaluation reports, Patient Leaders comment on group dynamics and lack of enthusiasm in participants. Two PLs felt they were initiating any interaction for the group. At times, some were afraid to voice their opinions in fear of how others would react.

“Gender balance is important.”

“We didn’t really gel or bond as a group.”

“The attitude of other participants was not always helpful.”

3.6 Suggestions for Improvement

Patient Leaders provided their thoughts in reflection sessions and in their evaluation reports on how the Patient Leaders Programme could improve for future cohorts.

- Involve older cohorts of Patient Leaders in the recruitment and interview process for new cohort.
- Provide IT support e.g. an hour in the office with no distractions for PLs to have access to a PC, printer, and stationery to do their work or report writing.
- Start work on the log book earlier & Introduce case studies earlier.
- Team up into pairs to work together outside session hours for mentorship and support on projects.