



Thames Valley and Wessex  
Leadership Academy

Oxford Academic  
Health Science Network



# **EVALUATION OF THE PATIENT LEADERSHIP DEVELOPMENT PROGRAMME PILOT FOR THAMES VALLEY - NHS ENGLAND, OXFORD ACADEMIC HEALTH SCIENCE NETWORK AND THAMES VALLEY AND WESSEX LEADERSHIP ACADEMY**

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**EVALUATION OF THE PATIENT LEADERSHIP  
DEVELOPMENT PROGRAMME PILOT FOR THAMES  
VALLEY - NHS ENGLAND, OXFORD ACADEMIC HEALTH  
SCIENCE NETWORK AND THAMES VALLEY AND WESSEX  
LEADERSHIP ACADEMY**

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# EVALUATION OF THE PATIENT LEADERSHIP DEVELOPMENT PROGRAMME PILOT FOR THAMES VALLEY - NHS ENGLAND, OXFORD ACADEMIC HEALTH SCIENCE NETWORK AND THAMES VALLEY AND WESSEX LEADERSHIP ACADEMY

## EXECUTIVE SUMMARY

This is an evaluation of the effectiveness of the Patient Leadership Development Programme Pilot for Thames Valley - NHS England, Oxford Academic Health Science Network and Thames Valley and Wessex Leadership Academy.

The evaluation consisted of in-depth semi-structured telephone interviews with the participants of the pilot programme as well as with the provider and commissioners of the programme. In addition, feedback from the 'Celebrating Success' day on 23rd July 2014 was incorporated in the evaluation.

### **The recommendations are as follows:**

1. Consideration should be given to redesigning the programme around the cohort of participants so that there are three parts; preparation (identifying people's objectives), the programme itself and follow up.

2. Preparation for the programme.

This should include:

- developing the programme to suit the level of experience of participants and type of input required whether at CCG or Area team or other level, for example those new to the role should receive practical support and the more experienced could undertake problem solving activities
- contacting the participants beforehand to ascertain their objectives, their view on how patients and NHS professionals can work together and if they have a focus on a specific condition or general patient involvement
- encouraging attendance by patient representatives and professionals from the same locality, ideally involving commissioners, providers, social care and the voluntary sector

3. The programme itself.

Key points include:

- clarity on objectives and outcomes for the programmes. Again this should be tailored to experience level of the participants
- input from experienced patient representatives to provide an insight into the knowledge and skills required as well as the practical aspects of the role
- a shift of emphasis to more activities and fewer taught sessions to enable interactive learning and problem solving, with more time allowed for networking. Consideration should be given to



reducing the length of the day's programme, incorporating the Action Learning Sets into the day and having space at the end of each day to review the learning.

- support and regular contact to be made available outside of the programme to patient representatives who may not be able to attend owing to illness

#### 4. Follow up and review of progress and development

- After delivery of a programme there should be provision of follow up support to facilitate continued development, particularly of patient representatives. This could include informal and formal networking, mentoring, guidance on where to go to find out about specific issues or concerns, setting up a bank of patient representatives who can be called on for advice or consultation and encouraging NHS professionals to continue to support patient representatives in their role.
- Scheduling a follow up meeting six to twelve months later to review progress and identify further training and development



## **INTRODUCTION**

This is an evaluation of the effectiveness of the Patient Leadership Development Programme Pilot for Thames Valley - NHS England, Oxford Academic Health Science Network and Thames Valley and Wessex Leadership Academy.

This pilot programme, consisting of two days of workshops and discussion groups plus Action Learning Sets, was run in the first half of 2014. The programme brought together patient representatives and NHS professionals with a view to developing patient leadership in the strategic thinking and planning process within NHS organisations.

The aim of the pilot programme was to lead changes in attitude, knowledge and behaviour as exemplified by:

- The cohort of patients and NHS colleagues will have trained and developed together enabling ongoing dialogue and joint working, supporting people who know what it's like to live with ill health to find creative solutions to health care challenges in partnership with clinicians, commissioners and managers.
- Patients will have increased confidence to work in partnership to create solutions, using their experiences constructively to work for change. They will also be able to demonstrate a commitment to work on their own personal development;
- Clinicians, practitioners and managers will have an improved understanding of the benefits of patient leadership and of the tools and models available to develop participation models within their own organisations;
- All participants will be able to develop local plans to put into action what they have learnt.

## **METHODOLOGY**

The evaluation consisted of in-depth semi-structured telephone interviews with the participants of the pilot programme as well as with the provider and commissioners of the programme. In addition, feedback from the 'Celebrating Success' day on 23rd July 2014 was incorporated in the evaluation.

The questions used in this evaluation are in Appendix A:

Areas covered in the evaluation included:

- the format, content, and delivery of the programme
- the learning gained from the programme
- the application of the knowledge, skills and behaviours gained from the programme to their own organisations
- identification of areas of innovation and /or good practice
- aspects of the programme that worked well or were useful
- aspects of the programme that did not work well or were not useful
- areas where the programme could be improved

All the information collected via the semi-structured interviews was received and treated with confidence and no individual is identified in this report



The evaluation was undertaken in July and August 2014.

The outcomes of this piece of work is a report summarising the findings of the telephone interviews and analysis of other feedback together with recommendations for future improvement of the programme.

## **FINDINGS**

Twenty-two people were identified for the evaluation including those from Clinical Commissioning Groups (CCGs) in the Thames Valley area and patient representatives as well as the provider and commissioners of the programme. A full list of those who were contacted are in Appendix B. Nineteen were interviewed, two did not respond to requests for interview and one declined to be interviewed.

### **Overall feedback**

There was a general agreement that the joint patient/professional approach was the right way to develop and improve patient participation and a few participants were very pleased to have been part of the pilot programme. There was a good interchange between participants although attendance was variable mostly by the NHS managers towards the end of the programme. It was noted that there was little diversity amongst the patient representatives with no representation from younger people, the lower socio-economic groups or carers.

It was also found that there were vulnerable people amongst the participants who required extra support and contact outside the programme to enable them to attend, and to ensure that they continued to be included if they were unable to do so owing to illness. There were also challenges as to what to do if a patient participant had a medical problem during a session.

### **Individual objectives for the programme**

Although the programme was developed with specific aims in mind, each interviewee was asked if they had their own objectives prior to attending the course and were asked if these had been achieved.

There were a range of responses including three participants who were just asked to attend the programme as they were in patient involvement/ representation roles to those who had specific objectives in mind. Three individuals said that they were new to the field of patient engagement whereas five had many years experience in this role working at the strategic level. A couple of patient representatives considered that their presence on the programme was observational rather than for their own development.

One participant commented that they were inspired to attend the programme following presentation by Mark Doughty of the Centre for Patient Leadership on how patients could contribute to service development and improvement.

Four were looking for a clear vision or a role model for patient leaders and five participants were looking to understand how to support better patient involvement and engagement including, for example:

- how to recruit a patient panel and what to do with it once this was convened
- writing a strategy for a CCG on patient involvement
- developing patient journey pathways based on actual experiences



- strengthening the patient input in the CCG assurance process
- demonstrating commitment and raising the profile of patient leadership by NHS organisations

There were comments about the programme being timely, even for those who had many years experience of being a patient representative, particularly in explaining the current NHS configuration and in understanding how patients and professionals can work together to find solutions. There was also a desire to gain the skills to become a patient leader, specifically:

- understanding influencing skills
- understanding negotiation
- having a broad view of the health network you are entering
- improving in confidence and assertiveness
- being a voice to influence change

One participant said that this programme provided an opportunity to reflect on how to improve on patient engagement.

There was a mixed response with respect to having achieved individual objectives including comments such as still not having clarity on what patient engagement looked like (despite having a session on a model of patient leadership in the programme) and realising that this programme was the beginning of a journey to a good dialogue being achieved between patients and NHS professionals. One participant was disappointed that programme did not follow that developed by Mark Doughty of the Centre for Patient Leadership, whereas another was very reassured that they were using the right skills and approach to building up patient leadership, coaching and influencing. A third commented that, as a result of attending the course, their patient engagement profile was raised in their local area and that others had begun to seek advice from them.

### **Learning from the programme including knowledge, skills, behaviours and innovations**

The programme provided much food for thought in that it highlighted the patient perspective, for example, how language is perceived; understanding the challenges faced by NHS managers; how NHS professionals could convey messages (e.g. using a video on a website rather than a script) ; how to achieve joint understanding of issues between patients and professionals; dealing with acronyms, and how to prepare papers before meetings so that patients are able to understand them.

In addition, the programme stimulated thinking in many areas such as how to engage patients in the CCG assurance process; the role of patient leadership in the executive function of the Local Area Team; how to champion for patient leadership; how to motivate patients; ensuring the statutory duty of patient involvement is taken on board by the CCG and developing patient leaders as a profession in a similar vein to managers or nurses.

There was an acknowledgement by one participant that from now onwards they would be more proactive as a patient representative and go and talk to NHS professionals about issues that concerned them. Similarly a manager said that they now had a bank of patients they could go to for advice or consultation and another considered asking patient representatives to carry out surveys on other patients to obtain views on prospective research projects.

There was a recognition that patient leaders had different levels of experience depending on the length of time of having been involved in this area as well as the type of engagement they were involved in , e.g. at practice, CCG or Local Area Team level. It was suggested that future patient engagement programmes should be developed to reflect this.



## **Programme areas that were useful or worked well**

There were three main areas where the programme worked well for most participants; networking with others, the coaching sessions and the Action Learning Sets.

The view on networking was that it was very helpful to have direct interaction with other patient leaders, to hear their concerns and experiences and to develop local contacts. For example, one participant provided advice to another on how to establish a patient representative structure across a number of CCGs or at Area Team level, using previous experience of setting up a nurse specialist service to manage the respiratory complications of patients with motor neurone disease. Another learned that widening the scope of influence was helpful in engaging the CCG in patient involvement issues.

It was considered that future programmes should allow more time for networking.

With regard to the coaching sessions, the participants were able to talk through how to plan patient engagement processes and to identify and deal with challenges. The feedback on coaching was variable as it was not clear to some participants exactly what the outcome should be and others had already had coaching in the past and did not see the need for further sessions.

The Action Learning Sets had a positive response generally as participants could use this space for the brainstorming of various issues, e.g. what to do with the patient panel once set up, building up relationships, having honest conversations and suggesting solutions. It was noted that the first Action Learning Set was very productive although the second was not due to reduced attendance notably by NHS personnel. There was a suggestion that mixing the Action Learning Set groups would further enhance their effectiveness.

The role play was considered to be useful by a few participants in that this helped prepare for patient engagement events in the context of public discussions about service changes and to gain an insight into the each other's views through role reversal.

For the less experienced participants the skills of chairing and contributing to meetings were found to be most helpful.

The presentations by Sir Muir Gray of Better Value Health Care and Dr Martin Burton of the UK Cochrane Centre were well received.

Generally learning together through activities was considered more effective than listening to speakers.

The mix of patient and professional participants was felt to be beneficial in that this provided a setting to have a balance of views, engender mutual respect, break down barriers and develop a willingness to share experiences.

## **Programme areas that were not useful or did not work well**

The areas that were not useful or did not work well were wide ranging reflecting the experience of the participants, for example many did not consider that the session on chairing a meeting necessary as they had this experience or were not required to fulfil that role. Uptake on the coaching was variable, some participants found that this worked very well for them whereas others did not. There was a similar reaction to speed dating with a preference for having a 'longer' date with half of the



group. There was also a request to learn some skills around assertiveness and other softer skills such as influencing and negotiation.

There were individual comments about not needing to know how NHS management worked but preferring an accurate map of the current NHS structure including the 'peripheral' organisations such as clinical networks, wanting less presentation and more group discussion and better preparation for the Action Learning Sets.

### **Structure and delivery of the programme**

In general the content of the programme, including background information, was well received although the balance between taught sessions and discussion groups was not right. There was agreement that this should have been in favour of more practical activities and that both days were too long overall in length.

Feedback on the facilitation, Action Learning Sets and coaching was good.

There was an issue with respect to one venue being unsuitable as there was very little parking space available, the lift had broken down and access to the wifi was not possible.

### **How could the programme be improved?**

Various suggestions were made on how future programmes could be improved and are listed below:

A. Prior to the commencement of the programme:

1. Asking the participants about their objectives prior to start of programme, for example sending out a questionnaire/telephoning to find out:

- whether they may have any specific objectives
- what is their idea of a patient leader
- whether they are interested in a specific condition or general patient engagement

B. The content of the Programme:

1. To clarify the programme objectives to answer the following questions:

- what is a patient leader?
- what is the role of a patient leader?
- what do NHS people need to do to help patient representatives, for example how can NHS managers improve the understanding of and best provide information to patient representatives and how can the chair of the group help that patient representative?
- what skills do patient representatives need?

2. Having the input of an experienced patient representative to present:

i. what knowledge and skills are required, i.e. someone who:

- is empowered
- can attend CCG, procurement or pathway redesign meetings
- can understand cost pressures between health, social care and Public Health
- be an advocate, contributor or listener and be trained up to do these based on their skill set (see model of patient representation below proposed by the lay member for NHS Bracknell and Ascot CCG)



- has influencing, assertiveness and negotiation skills
- ii. the practical aspects of being a patient representative, including:
- having some technical knowledge of conditions
  - be able to read large documents very quickly
  - understanding the time commitment involved
  - the need to do research
  - the need to talk to health professionals and managers and understand their language

### ***A model of patient representation***

*Aim: to create a pool of patients for the CCG to draw on for different functions*

*Four levels of interaction*

- 1. Listener (e.g. respond to consultations)*
- 2. Contributor (e.g. providing a support network)*
- 3. Advocate (e.g. sit on the GP council/federation of CCGs locally/disease specific groups for pathway design)*
- 4. Top level advocate (e.g. provide patient education)*

3. Provide the workshops for local health systems involving patient leaders in health, social and voluntary care sectors. These workshop should include providers as well as commissioners from all these sectors. There is a need to have GPs from CCGs on board so that they understand how to work together strategically with patients.

4. Provide activities:

- to show practical examples of patient engagement, for example how to make the best use of Patient Participation Groups, how to identify patient leaders for projects, demonstrate how the power of patient stories can be harnessed to redesign services and how best to communicate with patients
- by having examples of where patients can help each other (peer support group conversations)
- showing where patients and professionals work together in developing a care pathway across an area or analysing the process (co-production)
- to deal with real issues, modelling, testing of the status quo with the emphasis on practical approaches

5. Develop the programme to meet the needs of participants with different levels of patient experience leadership and organisations so that those new to the role receive practical support and the more experienced undertake problem solving activities

C. The structure of the programme:

- Build in flexibility so that patients and others can be followed up outside of the formal structure of the programme
- In order to keep the momentum going, have shorter days and weave the Action Learning Sets into the days rather than running them separately
- Facilitate better preparation for the Action Learning Sets, for example provide some guidance on what is appropriate for discussion.



- Have patients and NHS professionals attending in pairs to facilitate learning together and have the focus on effective working relationships rather than patient leadership
- Design the programme around the cohort of participants so that there are three parts to this; preparation (identifying people's objectives), the programme itself and follow up
- Bring people together at beginning and end of the day for review of the day's activities

#### D. Follow up and further support for patient leaders

There was a desire to have support following the programme, particularly for patient representatives to aid their continued development. Suggestions included:

##### i. Formal and informal networking including:

- post course buddying with a mix of patient leaders and NHS professionals
- regular contact through email
- setting up an online community, e.g. an area group for Thames Valley
- what to do for advice
- which groups to attend
- having a 'map' of various patient representatives for others to look up or contact, this should include a photograph of individuals

##### ii. Further training and development

##### iii. Guidance on who to ask for specific issues/concerns

##### iv. Setting up a 'bank' of patient representatives who can be called on for advice or consultation

##### v. Mentoring, with older cohorts working with those who have just finished a programme

##### vi. Guidance for NHS staff on how to support patient representatives, e.g.

- expectations of the patient role
- clarity on the application process to become a patient representative
- regular contact with the patient representative

##### vi. Meeting again in six to twelve months to review progress

## CONCLUSIONS

This programme was set up to try out different approaches to promoting patient leadership and enhancing the relationships between patients and NHS professionals. The approaches included a mixture of taught as well as interactive sessions with the aim of meeting the development needs of people who had a range of experiences in this area.

The programme was taxing and had to be delivered before the end of the financial year which led to only two suppliers being invited to bid and little time to ask people to attend.

The main benefit was that the programme created the right conditions for dialogue between patients and NHS professionals which had not been done before. This was an outcome that was desired by the commissioners and this will form the basis of strategic work for the next five years.



There was a lack of clarity about the aims and objectives of the programme by various participants which reduced the maximum benefit that could have been achieved by individuals, even though everyone was contacted prior to the programme by the provider requesting information on what people were wanting to gain from the course.

It was also clear that the right level for everyone was not achieved as the participants in the programme were diverse in their experiences. This led to some dissatisfaction and some difficulty in finding things in common.

Another key learning point was the need to provide support and contact to patient participants outside the programme to ensure that they continued to be included if they were unable to do so owing to illness.

The programme has shown that there is a clear need to invest in patient leaders in the same way as investing in other NHS staff so that they gain the right skills to do the job properly. It has also highlighted the issue of clarifying the role expected of patient leaders at different levels which perhaps could be formalised with job descriptions and person specifications.

Overall the programme was successful in demonstrating that patients and NHS professionals can work together in a strategic manner and that appropriate training and development can produce positive outcomes.

## **RECOMMENDATIONS**

1. Consideration should be given to redesigning the programme around the cohort of participants so that there are three parts; preparation (identifying people's objectives), the programme itself and follow up.

2. Preparation for the programme.

This should include:

- developing the programme to suit the level of experience of participants and type of input required whether at CCG or Area team or other level, for example those new to the role should receive practical support and the more experienced could undertake problem solving activities
- contacting the participants beforehand to ascertain their objectives, their view on how patients and NHS professionals can work together and if they have a focus on a specific condition or general patient involvement
- encouraging attendance by patient representatives and professionals from the same locality, ideally involving commissioners, providers, social care and the voluntary sector



### 3. The programme itself.

Key points include:

- clarity on objectives and outcomes for the programmes. Again this should be tailored to experience level of the participants
- input from experienced patient representatives to provide an insight into the knowledge and skills required as well as the practical aspects of the role
- a shift of emphasis to more activities and fewer taught sessions to enable interactive learning and problem solving, with more time allowed for networking. Consideration should be given to reducing the length of the day's programme, incorporating the Action Learning Sets into the day and having space at the end of each day to review the learning.
- support and regular contact to be made available outside of the programme to patient representatives who may not be able to attend owing to illness

### 4. Follow up and review of progress and development

- After delivery of a programme there should be provision of follow up support to facilitate continued development, particularly of patient representatives. This could include informal and formal networking, mentoring, guidance on where to go to find out about specific issues or concerns, setting up a bank of patient representatives who can be called on for advice or consultation and encouraging NHS professionals to continue to support patient representatives in their role.
- Scheduling a follow up meeting six to twelve months later to review progress and identify further training and development



## Appendix A

### Semi-structured Interview Questions

1. Name (including contact details)
2. Role (Patient /professional)
3. Organisation
4. Previous experience of patient and public involvement
5. What were your objectives for this programme?
6. Did you achieve them?
7. What have you learned from the programme?
8. What knowledge, skills and behaviours gained from the programme have you been able to apply to your own organisation?
9. Did you pick up any innovations or areas of good practice?
10. Which aspect of the programme was most useful to you personally? e.g. broadened horizons, new knowledge/understanding, networking etc
11. Which aspect of the programme was least useful to you personally? Why?
12. Any comments on the format, delivery and content of the programme?
13. Could the programme be improved? How?
14. Any other comments?



## Appendix B

### Contact List of Participants

| Name                | Role   | Organisation   |
|---------------------|--|--|
| Carol Munt          | Patient Partner & Advocate   | Lay Member NHS Thames Valley Patient Experience Strategy Group |
| Graham Smith        |  | NHS Aylesbury Vale CCG   |
| Helen Ward          | Senior Quality Manager   | Oxfordshire CCG  |
| Jan Fowler          | Director of Nursing and Quality  | NHS England Thames Valley Area Team                            |
| Jenni Lee           | Programme Director for BRC Translational Physiology Theme<br><br>Network Manager for Oxford AHSN Imaging Network | Oxford AHSN Imaging Network                                    |
| Karen Grannum       | CCG Manager  | NHS South Reading CCG  |
| Karen Maskell       | Lay member of CCG  | NHS Bracknell and Ascot CCG                                    |
| Kirsty Smith        |  | Oxford Health NHS Foundation Trust                             |
| Mark Stone          | Patient Rep  | Patient strategy group AHSN/Area Team<br>Clinical Senate       |
| Martin Harris       | Patient Rep  | Thames Valley Strategic Clinical Network                       |
| Nick Crowson-Towers | Patient Rep  | Thames Valley Strategic Clinical Network                       |
| Matthew Tait        | Area Director  | Thames Valley NHS England                                      |
| Neil Carter         | Patient Experience Lead  | Milton Keynes CCG  |
| Roberta Stewart     | Chair PPG, lay member of Wokingham CCG   | Wokingham CCG  |
| Sarah Wise          | CCG Manager  | North & West Reading CCG                                       |
| Wendy McClure       | Clinical Senate Manager  | Thames Valley NHS England                                      |
| Sian Rees           | Director   | University of Oxford Health Experiences Institute              |
| Steve Candler       | Senior Network & Domain Manager  | Thames Valley Strategic Clinical Networks, NHS England         |
| Ineke Powell        | Provider of the training programme   |  |
| Julie Kerry         | Assistant Director, Patient Experience   | NHS England Thames Valley Area Team                            |
| Sarah Pyne          | Patient and Public Involvement, Engagement & Experience Implementation Manager                                   | Oxford Academic Health Sciences Centre                         |
| Rosemary Balden     |  |  |

