

## No decision about me without me

**A strategy for working with patients, carers and the public to improve care delivery, commissioning, research and innovation across the Thames Valley and Milton Keynes**

### Contents

1. Introduction.....	2
What we want to achieve.....	3
How we will achieve this .....	4
2. Our approach .....	5
Our values and how we will work .....	5
Our model of involvement .....	6
3. Our Work.....	7
Developing patient leadership .....	7
Developing networks.....	7
Developing system assurance .....	8
4. Working with partners to develop person-centred care .....	8
Personalising care in organisations and healthcare systems .....	8
Personalising care for individuals .....	10
Understanding and using experience .....	10
5. Continuous learning .....	10
6. Innovation and research .....	10
Developing person-centred research .....	10
Thames Valley and Milton Keynes Patient Experience Operational Group.....	11
Thames Valley and Milton Keynes Patient Experience Oversight Group .....	14

## 1. Introduction

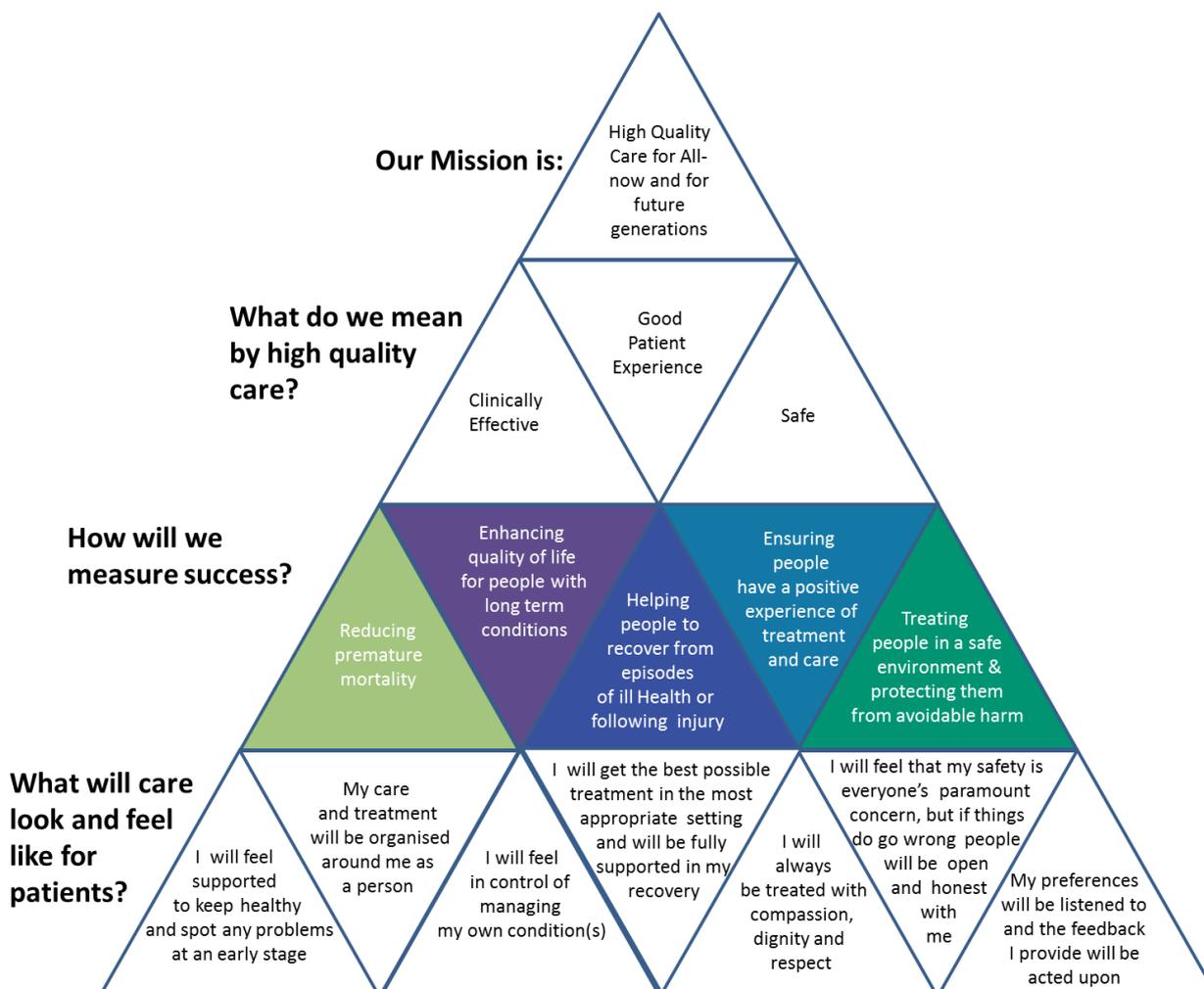
This strategy describes the approach of the Oxford Academic Health Science Network (AHSN), NHS England Thames Valley the Strategic Clinical Networks (SCNs) & Senate to support the delivery of high quality care and high quality research through the active involvement and engagement of patients, carers and the public<sup>◇</sup>.

Sustainable healthcare in the 21st century depends on people being actively engaged in maintaining their health, in managing the illnesses that affect them and being involved in designing and delivering healthcare systems. To achieve this we need a well-informed population, professionals that can engage with patients and carers as partners and person-centred healthcare that responds to what patients and the public need and say.

Our strategy will support the delivery of person-centred care by ensuring that patients, carers and the public are active partners in the work of our networks and programmes.

Our strategy builds on national policy, where patient experience is one of the three components of quality in healthcare, alongside clinical effectiveness and safety. Understanding and using what patients say to improve care is also central to national policy as shown in Figure 1.

**Figure 1: NHS England vision of Healthcare Quality**



<sup>◇</sup> For the purposes of this document the term lay people refers to patients, carers and the public

This is then supported by the more recent publication of the NHS Five Year Forward View, which articulates why change is needed, what that change might look like and how we can achieve it. It describes the need to engage with communities and citizens in new ways, involving them directly in decisions about the future of health and care services.

This document outlines:

- what we want to achieve
- how we will do this
- the approach we will take to working together as organisations and how we will work with lay people and others

**What we want to achieve**

Through this joint strategy we want to support and develop the delivery of high quality, person-centred care, research and innovation across the Thames Valley and Milton Keynes

**Person-centred care**  
Care that is responsive to and respectful of the needs, preferences and values of individuals

To make this possible we will need a network of committed senior leadership from both professionals and patients that will create change in individual care, organisational culture and systems of care.

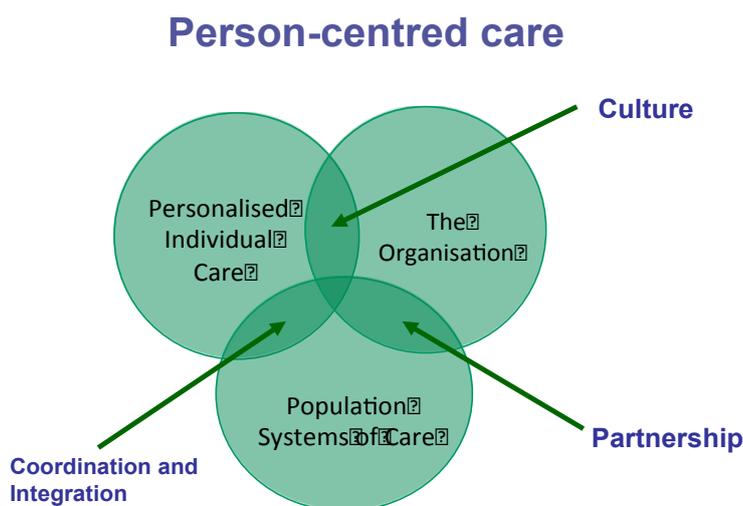


Figure 2

There is increasing evidence to suggest that person-centred care, or measures of positive patient experience are linked to positive clinical outcomes. For example, decreased mortality, rates of hospital-acquired infection and surgical complications. Positive patient experience is also linked to high levels of staff satisfaction. The opposite of this is also true as described by inquiries into failures of care, such as Mid-Staffordshire.

**How we will achieve this**

We will achieve high quality, person-centred care, research and innovation through:

1. **Involving patients, carers and the public in our work** to improve care delivery, commissioning, training, education, research and innovation for the whole population. We will involve lay people in the structures and processes of our work and support the organisations we work with to do this too. We will support lay people to be actively involved (see patient leadership paragraph 5, page 7).

**Involvement**  
 Working with patients, carers and the public to improve everyone's care  
 For example having patient representatives on boards and working groups helping to set priorities for research, co-designing programmes and services or educational training programmes

2. **Engaging patients and their families in their own health and care.** We will promote work that supports patients and carers to be actively engaged in their own care through personalised care planning, the better provision of health information and the measurement of outcomes that matters to them.

**Engagement**  
 Working with patients, their carers and families to personalise and improve their own care  
 For example through promoting shared decision making, personalised care plans, improving individuals' ability to find and use health information and routinely using patient and carer defined and reported outcomes and experience

### 3. and using experience: listening to and acting on what patients, carers and the public say.

We will promote the collection, analysis and usage of a wide range of data that describes patients' and the public's feelings about their involvement and engagement in care, research and innovation.

#### Understanding and using experience

Collecting, analysing, understanding and using the experience of patients, carers and the public to improve their care and the care of others

For example by using patient stories, analysing complaints data alongside survey data at ward level, using the results of the patient and staff survey

## 2. Our approach

In the autumn of 2013, we established the Thames Valley Patient Experience Strategy Group to develop our strategy and take forward our work plans. The Group includes organisational representation from Oxford AHSN, NHS England, the SCNs, clinical commissioning groups (CCGs), the third sector, healthcare trusts, Healthwatch, research organisations and local authorities (Appendix 1 and 2). We have appointed two lay representatives to the Group using a formal process including advertising the roles through Healthwatch.

An initial strategy document and work plan was written in the autumn of 2013. Both Oxford AHSN and NHS England held engagement events that helped to inform the plans. This document builds on this initial work and outlines the strategic direction going forwards. To reflect the increasing volume of work we are jointly, we revised our governance structure. We now have an Oversight Group to advise and help inform our strategy development and an Operational Group to oversee ongoing work (for Terms of Reference see appendix A and B). We have appointed lay members to both these groups.

### ***Our values and how we will work***

We believe that working in partnership with patients, carers and the public is essential to creating high quality, sustainable healthcare. We believe that for this to happen there has to be a shift in the way we think and the way we work with patients, carers and the public. Effective collaboration and coproduction can only happen with mutual understanding, respect and constructive challenge. We want to develop the support necessary for both lay people and professionals to be part of this type of on-going discussion.

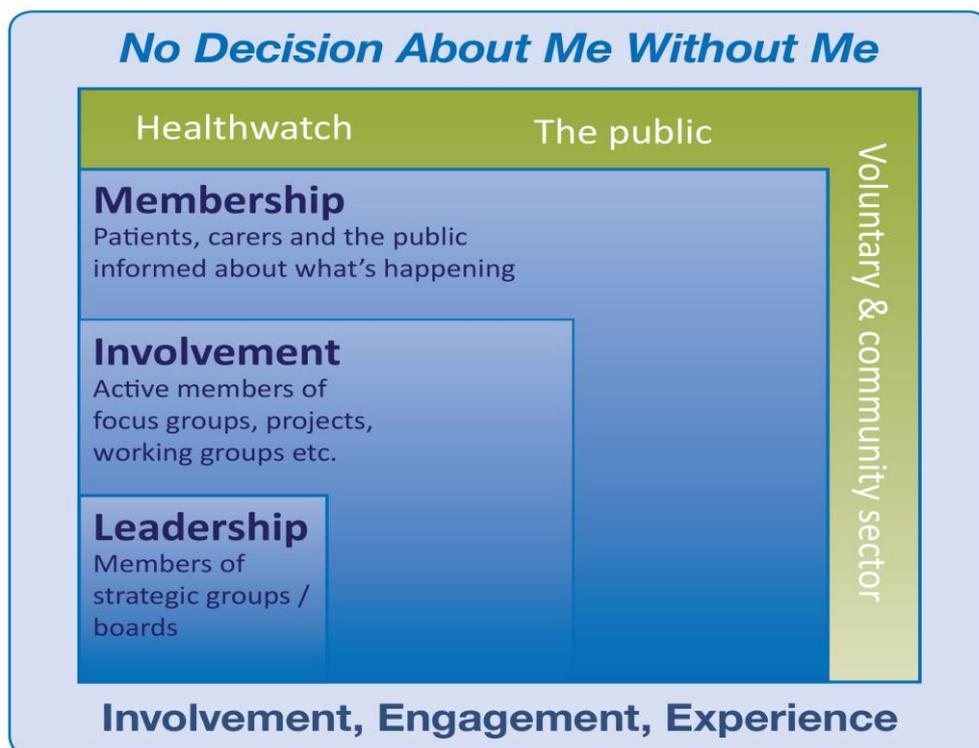
Our strategy will be developed and carried out by:

- doing things together – we will support patients, carers and the public to be involved throughout our work from shaping early thinking to evaluating the end result;
- being inclusive - we will actively involve all stakeholders, including those who are seldom heard and ensure that all our communications are accessible to all;
- doing things once and sharing – we will use existing expertise and structures whenever possible and we will coordinate our work with that of other organisations;
- being open about what we are doing and why.

**Our model of involvement**

We will actively involve patients, carers and the public in all aspects of the work we do. There are three possible ways in which lay people will be involved as shown in Figure 2.

**Figure 2 Our model of involvement**



All patients, carers and the public can be part of **Membership** if they wish to be kept informed of what is happening in health and social care in the Oxford AHSN, SCN and Senate, NHS England and other organisations.

Some members will become more actively involved. **Getting Involved** - for example, joining specific groups or helping with particular pieces of work. People who want to become more actively involved [**Part of the Team**] might be involved in on-going strategic planning of services or research. For example, as members of the Thames Valley Patient Experience Strategy Group, being involved with the Clinical Senate, sitting on the board of a local healthcare organisation. We will develop clear role descriptions for the lay people we involve. This will include being clear about whether we are asking for the individual perspective of those with lived experience of ill health or disability or whether we are asking for lay representation where individuals will need to be linked into and supported to provide the views of a broader community.

We have developed a lay payment policy in line with national guidance.

### 3. Our Work

#### ***Developing patient leadership***

Developing patient leaders is a key strategic priority nationally and is key to the successful delivery of our approach. Patient leadership is:

- creating an equal dialogue between patient, carers and the public and clinical and managerial leaders
- using patient leaders to build innovative, co-produced solutions to our health and healthcare challenges.

The Thames Valley Patient Experience Strategy Group, in conjunction with the Thames Valley Leadership Academy, have developed and run a pilot to train both lay people and professionals together as no existing training had taken this joint approach. Evaluation of the pilot has been very positive and we will be we will be commissioning further cohorts for lay people and professionals.

#### **Quote from a patient leader**

*"I sense that central government has left a lot of scope for us to design a system for Patient Involvement which best suits our local situation, so I would like to see:*

*A clear map of where the Patient Representatives will fit into the block diagram of the new NHS structure, with a local version of this to show the names of those who are so far involved, and also where the unfilled positions exist.*

*A clear description, rather than a specification, of the kinds of work, which a Patient Representative might expect to be involved with.*

*A recruitment strategy for new Patient Representatives, which will hopefully give all types of patients the opportunity to become involved if they want to.*

*Some training and continuing support, perhaps through 'buddying', for new Patient Representatives.*

*Some training for Patient Leaders, and continuing support for them.*

*The development of local communications and information gathering networks for each Patient Representative, to ensure that the views which they represent are from the whole spectrum of patient experience and not biased to favour complainants, who though very important in helping to address any deficiencies in the NHS, do to some extent constitute a self-selecting biased sample of patient experience.*

#### ***Developing networks***

This work will need the collaboration of a wide range of people and we will need to identify individuals and organisations interested in developing person-centre care and in improving patient experience. We will develop a network of patient and professional leaders with partner organisations to help with ideas, advice and delivery of our Strategy and work plans. In the spirit of collaboration and doing things once we are exploring how we might construct a database of interested people that can be shared across our organisations.

Alongside this we will map existing good practice, including availability of existing patient groups, determining geographical interest, expertise and gaps.

We are developing a communications and engagement plan to support the network. This will help to ensure that our work is informed by as wide a set of views as possible and that people are informed about what is happening across the Thames Valley and Milton Keynes. This plan will emphasise the need for two-way communication and will support our Strategy Group lay members to represent the views of others. The plan will include specific consideration of how to work with groups that are seldom heard, such as those with learning disabilities or refugees. As part of this two-way communication we will consult widely on an accessible version of our Strategy and our communications plan.

***Developing system assurance***

We will support and develop the mechanisms for incorporating lay perspective and advice into assurance processes.

**4. Working with partners to develop person-centred care**

Our partner organisations include Trusts, primary care, voluntary and private sector providers, health and local authority commissioners, our universities and industry.

***Personalising care in organisations and healthcare systems***

Person-centred care is more than ensuring that the care of individual patients addresses their individual needs and preferences. It is about the way in which organisations and systems respond to the reasonable demand ‘no decision about me without me’. It is about the way in which we involve patients and the public in, for example, our committees and boards, designing services and in education and training programmes. It is about the way we collect individuals’ experience of health and healthcare and use this to improve care for everyone.

Person-centred care is fundamentally about leadership, culture and relationships and is expressed in all aspects of care quality: in patient experience, safety and clinical outcomes.

We want to support cultures where patient’s suggestions are listened to as well as complaints, where patients know what to expect, and they experience kindness and compassion, where patient pathways are mapped out so that patient’s will understand them.

Organisations that do well on measures of patient experience share some common characteristics. These are outlined on page 9.

**Characteristics of organisations that deliver person-centred care:**

**Committed senior leadership**

1. From the chief executive, the Board and senior clinicians
2. Person-centred care central to the strategic vision - experience and quality alongside finance
3. Vision communicated and embedded alongside mechanisms for accountability

**A comprehensive, organisation wide framework**

4. Quality initiatives important but not enough, cultural change is a necessity
5. Integrated care; across conditions, organisations and sectors

**Support staff – ‘caring for the carers’**

6. Collect and act on staff experience data
7. Staff objectives include the delivery of person-centred care
8. Training and development to support delivery of person-centred care
9. Public reward for innovation such as positive change in practice and improved patient experience

**Engage patients and their families in the organisation of their own care - personalise care**

10. Personalised care plans
11. Shared decision making
12. Supporting patients and the public to improve their health and access healthcare when they need it
13. Measure the experience of care and use patient and carer defined and reported outcomes

**Involve the public and patients in the structures and processes of service delivery, research and innovation**

14. Governance structures and processes
15. Service design
16. Teaching and training
17. Research and innovation

**Measure and use patient experience data**

18. Collect a range of data: real-time, experience, opinion, complaints, safety etc. using it to measure, monitor and benchmark service quality
19. Listen to individual patient stories

**Generate a culture of learning and change**

20. Understand and act on the things that go wrong
21. Define the things that should always happen – ‘always events’

Many of our organisations currently do some of these things well; few will do all of them as well as they could. We want to make sure that we support innovation and the adoption of best practice in person-centred care as well in other aspects of healthcare such as drugs and diagnostic tests.

We want to work with all partner organisations to develop a framework for patient and public involvement, engagement and experience. This will include how best to measure and use the broad range of experience data available for innovation in service delivery, research, education and training: from use of individual patient stories to social media comments, the friends and family test, survey responses, complaints and safety data. The

framework will also include how to support staff to provide person-centred, personalised care as there is, unsurprisingly, an association between positive staff experience and positive patient experience.

#### *Personalising care for individuals*

The population is aging and the number of people with at least one long-term illness is increasing. These changes put pressure on the healthcare system. We need to help people to stay well and to support them to manage illnesses when they occur. To make this possible care needs to be personalised. Personalised care means that there is a discussion, or number of discussions, between a patient and a health professional that clarifies what needs to be achieved, what the options are for getting there and what the patient prefers. This discussion should result in a plan of action, a personalised care plan, based on the understanding developed between the patient and the professional.

#### *Understanding and using experience*

Currently national quality dashboards and metrics do not take into account real time patient experience and the information collected is not necessarily representative of what is important to patients. The Friends and Family test aims to provide a simple headline metric, which can be used to drive cultural change and continuous improvements in quality of care received by NHS patients. We will work with our partners to develop the understanding and use of experience data for quality improvement.

### 5. Continuous learning

Joint working with Health Education Thames Valley will explore the ways in which patients, carers and the public can be involved in the range of teaching activities from curriculum design to examinations and how patient stories and experience data can be incorporated routinely into teaching.

This will be supported by developing a module on person-centred care for the Evidence-based medicine MSc and through seminars and lectures.

### 6. Innovation and research

The role of patients in innovation, from adoption to diffusion will be explored and included in AHSN plans and network development. Patients and the public will be integral to the process of assessing the need for innovation and assessing what should be implemented.

We will consider further ways to support innovation in person-centred care.

#### *Developing person-centred research*

We will meet regularly with the key research organisations in the Network: the Oxford NIHR Biomedical Research Centre (BRC), the Oxford Academic Health Science Centre (AHSC), the Collaboration for Applied Health Research and Care (CLAHRC) and the Clinical Research Network (CRN). We will develop a joint approach to areas of overlapping work such as training, impact measurement and communications.

## **Thames Valley and Milton Keynes Patient Experience Operational Group**

### **No decision about me, without me**

#### **Terms of Reference**

##### **Background and Purpose**

To provide delivery to the joint patient and public involvement, engagement and experience work of NHS England South (Central – Thames Valley), the Thames Valley Strategic Clinical Networks (TV SCNs) and the Oxford Academic Health Science Network (AHSN), as described in the joint strategy No decision about me, without me. This joint strategic work includes:

- Involvement: working with patients, carers and the public to improve care delivery, training, education, research and innovation for the whole population
- Engagement: working with patients and their families to improve their own care
- Experience: listening to and acting on what patients, carers and the public say - collecting, understanding and using patients' and the public's feelings about their involvement and engagement in care, research and innovation.

The purpose of the Operational Group is to provide delivery of the strategy.

The strategy will include individual workplans for the three sponsor organisations. The named contacts responsible for the delivery of the individual organisation work plans are detailed below:

- Oxford Academic Health Science Network – Sian Rees
- NHS England Patient Experience Team – John Trevains
- NHS England Clinical Senate and Strategic Clinical Networks – Wendy McClure

In addition, the Group will:

- Share information on our work with patient and public groups and health and social care organisations;
- Collect and act on views about our work from patient and public groups and health and social care organisations.
- Report progress to the Oversight Group
- Provide a regular reporting mechanism for programmes of work such as The Leading Together Programme.
- Coordinate and align work plans

### **Principles of working**

No decision about me, without me – this means:

- Doing things together - we will support patients, carers and the public to be involved throughout our work from shaping early thinking to evaluating the end result.
- Being inclusive - we will actively involve all stakeholders, including those who are seldom heard and ensure that all our communications are accessible to all.
- Doing things once and sharing - we will use existing expertise and structures whenever possible and we will coordinate our work with other organisations.
- Being open about what we are doing and why.

### **Confidentiality**

Please be aware of your obligations with respect to the confidential handling of information originating from any meeting of the Patient Experience Operational Group for the Thames Valley and Milton Keynes. In fulfilling your role on this group you might have to access such confidential data in relation to policies, patients and staff. You must be aware of the importance of observing and protecting patient and staff confidentiality when handling this information. You must therefore limit access to such information to that strictly necessary to carry out tasks appropriate to the Patient Experience Operational Group for the Thames Valley and Milton Keynes and to keep any such information confidential.

### **Secretariat**

Emma Robinson, NHS England South (Central) will act as Secretariat to the Oversight Group.

### **Frequency of meetings**

The Operational Group will hold meetings every six weeks.

### **Chairing**

The Group will have professional and lay co-chairs.

### **Membership**

The Group will have at least two lay members, appointed through open interview.

The Group will have representation from the three sponsor organisations: NHS England Patient Experience Team, NHS England Clinical senate/Strategic Clinical Networks and Oxford AHSN.

Additional members may be called upon for ad-hoc support as required

### **Core Membership**

Oliver Evans                      Communications and Engagement Lead Manager, CRN: Thames Valley and South Midlands

Julia Coles                         Senior Clinical Network Manager, NHS England

Kathryn Cooper	Patient Experience Manager, NHS England (South Central)
Douglas Findlay	Lay Partner (co-chair)
Lynne Maddocks	Coordinator of Patient & Public Involvement Nuffield Department of Primary Care Health Sciences, University of Oxford
Wendy McClure	Clinical Senate Manager, Thames Valley Strategic Clinical Networks and Senate
Sandra Regan	Patient Involvement and James Lind Alliance Project Manager NIHR Oxford Biomedical Research Centre & Musculoskeletal Biomedical Research Unit
Sian Rees	Director for Patient and Public Involvement, Engagement and Experience, Oxford Academic Health Science Network (AHSN)
Emma Robinson	Patient Experience Lead, NHS England (South Central)
Rebecca Day	Lay Partner
John Trevains	Assistant Director of Nursing, NHS England (South Central)
Nick Fahy	NIHR Oxford Biomedical Research Centre (BRC)
Diane Hilson	Oxford Academic Health Science Centre coordinator
Paul Hewitson	Research and Design Service, Nuffield Department of Public Health, University of Oxford

### **Thames Valley and Milton Keynes Patient Experience Operational Group Group Principles of Behaviour**

- There is mutual respect between members, who are supportive of each other, non-judgemental, respect difference and listen to people's views
- Everyone is equal
- We have collective responsibility for the group
- Send apologies in advance
- Start and end meetings punctually
- Have mobile phones off
- Maintain confidentiality - in the room
- Treat others as you would like to be treated yourself
- Listen actively and show respect, especially during lively discussions
- Use clear and concise information
- Accept that it's O.K. to have a bad day
- Take responsibility for looking after yourself
- Feel free to take time out if you need it
- Assume good will
- If you challenge, challenge the statement and not the person

May 2016

## **Thames Valley and Milton Keynes Patient Experience Oversight Group**

### **No decision about me, without me**

#### **Terms of Reference**

##### **Background and Purpose**

To provide advice and oversight to the joint patient and public involvement, engagement and experience work of NHS England South (Central – Thames Valley), the Thames Valley Strategic Clinical Networks (TV SCNs) and the Oxford Academic Health Science Network (AHSN), as described in the joint strategy No decision about me, without me. This joint strategic work includes:

- Involvement: working with patients, carers and the public to improve care delivery, training, education, research and innovation for the whole population
- Engagement: working with patients and their families to improve their own care
- Experience: listening to and acting on what patients, carers and the public say - collecting, understanding and using patients' and the public's feelings about their involvement and engagement in care, research and innovation.

##### **Oversight Group Objectives**

The Oversight Group will provide advice and critical friend input, including:

- Influencing strategic direction
- Ensuring a wide group of stakeholders are involved
- Providing assurance to the AHSN Board and the NHS England South (Central) Directors
- Supporting dissemination of the joint strategy and its key messages

##### **Governance**

Accountability of the joint strategy is with Oxford AHSN and NHS England South (Central). All members of the Group will have a voice in the decision making and strategic vision. Outputs and information from the Group will be made accessible to all.

##### **Chairing**

The Group will have a professional and lay co-chair.

The chair of the Group will rotate every year.

### **Secretariat**

NHS England South (Central) will provide the Secretariat.

### **Frequency of meetings**

The Oversight Group will meet three times a year in its first year of operation. This will be reviewed at the end of this period. Members may be called upon for ad-hoc support as required.

### **Confidentiality**

Please be aware of your obligations with respect to the confidential handling of information originating from any meeting of the Patient Experience Operational Group for the Thames Valley and Milton Keynes. In fulfilling your role on this group you might have to access such confidential data in relation to policies, patients and staff. You must be aware of the importance of observing and protecting patient and staff confidentiality when handling this information. You must therefore limit access to such information to that strictly necessary to carry out tasks appropriate to the Patient Experience Operational Group for the Thames Valley and Milton Keynes and to keep any such information confidential

### **Membership**

The following partner organisations will be represented. Members will be responsible for disseminating information back to their respective organisations and related forums

The Group will invite representation from the following partner organisations, which will also reflect the geographical spread of Thames Valley:

- Clinical Commissioning Groups – David Smith
- Provider organisations – Dr Minoo Irani
- Third sector organisations – Helen Garforth
- Healthwatch – Ollie Grice
- Local Authorities – (tbc)
- Research organisations – Trish Greenhalgh
- Research Lay Partner – Karen Swaffield
- Thames Valley & Wessex Leadership Academy – Caroline Chipperfield
- Oxford AHSN – Sian Rees
- NHS England (South Central) – Jan Fowler
- Oxford AHSN Lay partner – Douglas Findlay
- Thames Valley Lay partner – Karen Maskell
- Thames Valley Health Education – Pauline Brown
- NHS England Communications Team – Gayle Rossiter
- Royal Berkshire Research & Development lead clinician – Atul Kapila
- Buckinghamshire NHS Foundation Trust – Caroline Morrice