

People with Lived Experience Involvement Policy

Document Reference No.	To be allocated by the Policy Manager when document is approved
Replacing document	
Target audience	Trust Wide
Author	Strategic Programme Performance Improvement Manager
Group responsible for developing document	Trust Wide Patient Experience Group
Status	Draft
Authorised/Ratified By	Trust Wide Patient Experience Group
Authorised/Ratified On	Date when document was ratified
Date of Implementation	Date to be included only when the document goes live – normally when it was ratified
Review Date	2017
Review	This document will be reviewed prior to review date if a legislative change or other event otherwise dictates.
Distribution date	Date when the document was issued and made available on Intranet/Internet
Number of Pages	Number of pages
Contact Point for Queries	policies@kmpt.nhs.uk
Copyright	Kent and Medway NHS and Social Care Partnership Trust 2014

DOCUMENT TRACKING SHEET

People with Lived Experience Involvement Policy

Version	Status	Date	Issued to/approved by	Comments
0.1	Draft	03/06/14	Trust Wide Patient Experience Group	

REFERENCES

<p><i>'Reward and Recognition: The principles and practice of service user payment and reimbursement in health and social care'.</i> (Department of Health - August 2006) http://www.shapingourlives.org.uk/documents/DH_RewardandRecognition.pdf</p>
<p><i>'Encouraging user involvement in Mental Health services.'</i> (Journal of Continuing Professional Development, RCP, L. Taite and H. Lester - 2005) http://apt.rcpsych.org/content/11/3/168.full.pdf</p>
<p><i>'Health and Social Care Act':</i> 2001, Section 11 http://www.legislation.gov.uk/ukpga/2001/15/section/11</p>
<p><i>'The NHS Constitution: The NHS Belongs to Us All'</i> : 2013 https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/170656/NHS_Constitution.pdf</p>

RELATED DOCUMENTS

<p><i>'An Appreciative Inquiry: Supporting service users to help the Trust improve'</i> http://www.kmpt.nhs.uk/Downloads/Getting-involved/Appreciative-Enquiry-report.pdf</p>	(KMPT, 2010)
<p><i>'Community Engagement Strategy'</i> http://staffzone.kmpt.nhs.uk/Downloads/staffzone/strategies/2012V1.00CommunityEngagementStrategy.pdf</p>	(KMPT, 2011)

CONTENTS

1	INTRODUCTION	4
2	PURPOSE.....	4
3	DUTIES	5
4	SYSTEMATIC INVOLVEMENT:.....	7
5	INVOLVEMENT LEVELS:.....	7
6	EXPANDING PARTICIPATION:	9
7	IMPLEMENTATION INCLUDING TRAINING AND AWARENESS.....	9
8	STAKEHOLDER, CARER AND USER INVOLVEMENT/CONSULTATION	10
9	EQUALITY IMPACT ASSESSMENT	10
10	HUMAN RIGHTS	10
11	MONITORING COMPLIANCE WITH AND EFFECTIVENESS OF THIS DOCUMENT	10

APPENDICES

- A EQUALITY IMPACT ASSESSMENT
- B ABBREVIATIONS AND DEFINITIONS
- C PERSONS/GROUPS INVOLVED IN DEVELOPMENT AND CONSULTATION
- D FORMS
- E OTHER RELATED INFORMATION

1 INTRODUCTION

- 1.1 There is a strong history in KMPT of engagement with experts by experience and a recognition that the involvement of people who use services is a prerequisite to the delivery of the Trust vision and clinical strategy.

*“Deliver excellent care personal to you, delivering quality through partnership.
Creating a dynamic system of care, so people receive the right help, at the
right time, in the right setting with the right outcomes”*

Kent and Medway Partnership Trust, Vision

- 1.2 By listening to and involving people with lived experience in improvement activities, we will be best placed to deliver quality services that are responsive to local needs and support:
- 1.2.1 Provision of excellent community services close to home.
 - 1.2.2 A focus on the recovery approach ensuring positive outcomes and partnership working.
 - 1.2.3 Improvement to the quality and dignity in services.
 - 1.2.4 Expansion of our strongest specialist services where appropriate.
- 1.3 The Transformation Programme is the vehicle through which the Trust is delivering on a number of service developments and improvements. Achieving cultural change and developing excellent recovery oriented care will be an ongoing and major strand of work that will underpin and enable the Transformation Programme.
- 1.4 To recognise and value the contribution of people with lived experience in consultancy roles this policy has been developed. It builds on national guidance (*Reward and Recognition, 2006*) about equitable remuneration and seeks to increase the breadth and depth of involvement.

2 PURPOSE

- 2.1 Government policy promotes the involvement of people with lived experience¹ in the development and delivery of local services. In 1990, the *NHS and Community Care Act* was the first piece of UK legislation to establish a formal requirement for user involvement in service planning and this has been repeated many times since e.g. Section 11 of the Health and Social Care Act (2001). The Department of Health issued *Reward and Recognition* in 2006 to set out involvement principles and to give practical advice for remunerating people with lived experience involved in service improvement activities.
- 2.2 A cultural shift is beginning to emerge whereby involving people with lived experience is no longer perceived as just a political mandate. Rather there is an increasing awareness that involvement is a genuinely worthwhile activity with a range of benefits. In KMPT our experience over the past 10 years has demonstrated that individuals who have used services are a valued resource that,

¹ The term ‘people with lived experience’ is used to describe all people who use our services. This may include service users, their families and carers.

when properly engaged, can help us to improve the services which we provide. People with lived experience have a unique understanding of mental distress and can offer a different perspective about illness and care.

- 2.3 This document sets out the principles and practice for remunerating service users, carers and volunteers for their involvement in service improvement activities. It identifies opportunities to engage with a wider network of people with lived experience and to prompt staff to automatically seek involvement opportunities.

2.3.1 Systematic involvement:

Establish mechanisms that will stimulate the involvement of people with lived experience in all improvement activities.

2.3.2 Involvement levels:

Define the levels of involvement and associated reimbursement / payment mechanisms.

2.3.3 The responsibilities of people with lived experience whilst engaged in improvement activities:

Describe the responsibilities of people with lived experience and provide information which will support those with lived experience to make informed choices about being involved.

2.3.4 The responsibilities of KMPT when working with people with lived experience who are engaged in improvement activities:

Describe KMPT responsibilities.

2.3.5 Expanding participation:

Identify opportunities for widening participation and introduce principles that will stimulate flow through the involvement community.

3 DUTIES

3.1 The role of all staff

- 3.1.1 All staff should be aware of the involvement opportunities for people with lived experience and, where appropriate, actively promote these opportunities. One mechanism for having this conversation includes an 'exit interview'. (Appendix E, i).

3.2 The role of staff leading on improvement activities and service redesign

-
- 3.2.1 Lead staff member engaged in improvement activities and service redesign should seek to involve people with lived experience in the planning, design and implementation stages.
 - 3.2.2 Lead staff member should clearly define and mutually agree the involvement activities before the project starts, particularly the involvement level and ensure that this is made clear to the person with lived experience. The agreed involvement relationship will be summarised in writing (Appendix D, iv).
 - 3.2.3 The definition of the project and the involvement level may change over time and the agreed involvement relationship should be reviewed at least six monthly.
 - 3.2.4 Lead staff member should ensure that the appropriate level of funding is obtained for the expert involvement before the work commences.
- 3.3 The role of the Patient Experience Team
- 3.3.1 To provide expertise and information to people with lived experience who express an interest in becoming engaged in improvement activities.
 - 3.3.2 To provide administrative support to the practical running of an 'Involvement Network'. (Appendix E, ii). This will include the responsibility for completing an induction checklist with the person with lived experience (Appendix D, i).
 - 3.3.3 To ensure that both payment and reimbursement policies are written in plain English and made available in different formats to ensure they are fully accessible. This must include signposting on where advice on benefits can be obtained.
 - 3.3.4 Facilitate opportunities for prospective Involvement Network members to 'buddy' with others who have existing experience in participating in involvement activities.
- 3.4 The role of the Programme Management Office
- 3.4.1 To set up and implement a process that will prompt the involvement of people with lived experience at the design stage of all planned service developments. This will include identification of adequate funding for the payment of expert by experience involvement in the associated Business Case or Project Implementation Document. (See section 4 and Appendix D, ii).
- 3.5 The role of the Human Resource Directorate
- 3.5.1 To provide advice on employment law.
 - 3.5.2 Work with the Patient Experience Team to facilitate access to relevant training for experts by experience engaged in involvement activities.
- 3.6 The role of the Finance Directorate

-
- 3.6.1 Ensure that both payment and reimbursement policies are compliant with the associated financial obligations.
 - 3.7 The role of people with lived experience engaged in involvement activities
 - 3.7.1 To understand and agree to the terms and conditions upon which they get involved, be it on a paid basis or on a voluntary basis (Appendix D, iii).
 - 3.7.2 To be aware of what is expected of them in relation to the specific involvement activity and what support they are entitled to.
 - 3.7.3 Responsible for declaring any earnings to the tax and benefit offices as appropriate.
 - 3.8 The role of people with lived experience in receipt of benefits
 - 3.8.1 In addition to the roles and responsibilities set out above, people with lived experience in receipt of benefits should be aware that fee payments and expenses reimbursement can impact on their benefit conditions. People should be encouraged to take opportunities to discuss benefits and the impact of payments on them.

4 SYSTEMATIC INVOLVEMENT:

- 4.1 The Trust will actively involve people who have used services in all improvement and service development activity.
- 4.2 The Programme Management Office project initiation checklist, which must be completed at the beginning of any service development activity, will ask whether people with lived experience have been or should be involved during the design, planning and implementation stages.
- 4.3 Business Case and Project Implementation Documentation will include a section where the practical and financial provisions for involving people with lived experience are considered up front.
- 4.4 By scoping involvement opportunities for people with lived experience at the planning stage, the Trust will be in a position to provide greater notice about involvement opportunities. This is important for people with lived experience, who report that it is helpful to receive 4-6 weeks notice.

5 INVOLVEMENT LEVELS:

- 5.1 There are a range of ways in which people with lived experience can be involved and it is important to be clear about the difference in these levels so that they can make an informed choice about the arrangements concerning their involvement.
- 5.2 There are three levels of involvement

5.2.1 Volunteering:

Volunteering is when people give their time and skills for the benefit of services without concern for financial gain.

5.2.2 Contributing:

People with lived experience contribute their expertise to decisions made within the Trust. This may include:

- Participation in meetings
- Taking part in recruitment
- Undertaking audits, delivering surveys, and other types of service evaluation techniques
- Delivery or participation in ad hoc, short term or one off training

5.2.3 Co-producing:

People with lived experience and staff undertake 'task and finish' activities together in partnership. This may include:

- Specific technical contribution
- Higher level of autonomy and responsibility
- Contribution to academic activity

5.3 For effective involvement, people need to feel supported, and for their contribution to be valued.

5.4 The level of involvement that an individual wishes to be engaged in is determined personally and may be re-negotiated at any time.

5.5 Involvement levels are fluid and it is possible to be engaged at more than one level at any one time if the person with lived experience is involved with multiple projects.

5.6 The Trust must be clear at the beginning of the involvement activity about the terms of engagement, this will include agreement about the level of involvement activity up front (Appendix D iv).

5.7 The Involvement Network will be used to identify an individual with an indicated preference for being involved at the level required for the specific, defined task.

5.8 People with lived experience should not be left out of pocket or put at risk of being financially worse off as a result of their involvement in service improvement.

5.9 The contribution people with lived experience make can be recognised and valued in all sorts of ways such as being thanked, positive feedback and acknowledgement, staff time, practical assistance, training, personal development or seeing the impact of the work and changes made as a result of involvement. Payment can also be offered for certain levels of involvement.

Level	Involvement description	Remuneration
-------	-------------------------	--------------

Volunteering:	Volunteering is when people give their time and skills for the benefit of services without concern for financial gain.	Expenses only
Contributing:	Experts by experience contribute their expertise to decisions made within the Trust.	Lower rate of pay (plus expenses)
Co-producing:	Experts by experience and staff undertaking 'task and finish' activities together in partnership.	Higher rate of pay (plus expenses)

5.10 The rate of pay will be reviewed annually. (Appendix E, iii).

6 EXPANDING PARTICIPATION:

- 6.1 To foster meaningful involvement we will seek to broaden our involvement network and will actively seek the views of those who will challenge us. No one should be excluded from having the opportunity to become involved.
- 6.2 We will introduce a set of principles that will stimulate flow through the involvement community so that we can encourage wider participation. (Appendix E, iv).
- 6.3 All staff will be encouraged to discuss involvement opportunities at appropriate points in the care pathway and to complete an 'exit interview' with service users and carers, to ensure that everyone who uses our services is aware of the ways in which they can become involved. (Appendix E, i)
- 6.4 The Trust will develop an 'Involvement Network' which will provide a register of people with lived experience who have indicated an interest in participating in involvement activities. People with lived experience will be able to determine their skill set, in conjunction with the Patient Experience Team, level of preferred involvement and information about their availability.
- 6.5 Those joining the network should be advised of the opportunity to become a Foundation Trust public member. All new Foundation Trust Public members will be provided with information about the Involvement Network.
- 6.6 Involvement opportunities will be advertised and promoted through a variety of mechanisms, which may include the Involvement Network, service user forums, the Trust website, Live It Well, social media and local media (.e.g. newspapers and radio).
- 6.7 There may be occasions when it is appropriate to invite specific groups to become involved, based on their particular area of experience and expertise.

7 IMPLEMENTATION INCLUDING TRAINING AND AWARENESS

- 7.1 The Policy will be published on the Trust intranet, and its launch communicated through Directors and Senior Managers for their services.
- 7.2 The Policy will be shared with people with lived experience already known to be engaged with involvement activities, with service user forums and with partner organisations.

8 STAKEHOLDER, CARER AND USER INVOLVEMENT/CONSULTATION

- 8.1.1 A group of people with lived experience already known to be engaged with involvement activities and a selection of key staff members were involved in the development of the Policy.
- 8.1.2 Each of the Service Lines were involved in the development of the Policy.
- 8.1.3 A wide range of stakeholders were consulted, including experts by experience already known to be engaged with involvement activities, service user forums, KMPT staff and partner organisations.
- 8.1.4 The Policy was presented to the Trust Wide Patient Experience Group for discussion (TO BE APPROVED).

9 EQUALITY IMPACT ASSESSMENT

- 9.1 The Equality Act 2010 places a statutory duty on public bodies to have due regard in the exercise of their functions. The duty also requires public bodies to consider how the decisions they make, and the services they deliver, affect people who share equality protected characteristics and those who do not.
- 9.2 In KMPT the culture of Equality Impact Assessment will be pursued in order to provide assurance that the Trust has carefully considered any potential negative outcomes that can occur before implementation. The Trust will monitor the implementation of the various functions/policies and refresh them in a timely manner in order to incorporate any positive changes.

10 HUMAN RIGHTS

- 10.1 The Human Rights Act 1998 sets out fundamental provisions with respect to the protection of individual human rights. These include maintaining dignity, ensuring confidentiality and protecting individuals from abuse of various kinds. Employees and volunteers of the Trust must ensure that the trust does not breach the human rights of any individual the trust comes into contact with. If you think your policy/strategy could potentially breach the right of an individual contact the legal team.

11 MONITORING COMPLIANCE WITH AND EFFECTIVENESS OF THIS DOCUMENT

- 11.1 The Involvement Network will be held by the Patient Experience Team and activity will be reported to the Trust Wide Patient Experience Group.
- 11.2 The Programme Management Office will hold records of service development checklists and will report to the Patient Experience Team on the prevalence of involvement of people with lived experience in development plans.

<i>What will be monitored</i>	<i>How will it be monitored</i>	<i>Who will monitor</i>	<i>Frequency</i>	<i>evidence to demonstrate</i>	<i>Action to be taken in event of non</i>
-------------------------------	---------------------------------	-------------------------	------------------	--------------------------------	---

				<i>monitoring</i>	<i>compliance</i>
Involvement Network membership	Report to the TWPEG on the number of members, highlighting new membership and turnover.	Patient Experience Team	Quarterly	▪ Report	▪ Review mechanisms for expanding participation.
People with lived experience involvement in service development	Report to Patient Experience Team on the prevalence of people with lived experience becoming involved at the definition stage of project plans.	Programme Management Office	Quarterly	▪ Report	▪ Review mechanisms for identifying involving people with lived experience.

APPENDICES

APPENDIX A EQUALITY ASSESSMENT SCREENING

General Information	
Name of function:	Policy
Directorate:	Nursing
Function Owner:	Pippa Barber
Date of screening:	June 2014
Is this a proposed, new or existing function?	Existing function
Aims of function and monitoring arrangements	
<p>To ensure we promote and encourage meaningful involvement of people with lived experience, in a fair and equitable way, KMPT must take this opportunity to review our approach to involvement.</p> <p>This document sets out the principles and practice for remunerating service users, carers and volunteers for their involvement in service improvement activities. It identifies opportunities to engage with a wider network of people with lived experience and to prompt staff to automatically seek involvement opportunities.</p> <p>Systematic involvement: Establish mechanisms that will stimulate involvement of people with lived experience in all improvement activities.</p> <p>Involvement levels: Define the levels of involvement and associated reimbursement / payment mechanisms.</p> <p>The responsibilities of people with lived experience engaged in improvement activities: Describe the responsibilities of people with lived experience engaged in improvement activities and provide information which will support people with lived experience to make informed choices about being involved.</p> <p>KMPT responsibilities: Describe KMPT responsibilities.</p> <p>Expanding participation: Identify opportunities for widening participation and introduce principles that will stimulate flow through the involvement community.</p>	

Do you monitor the policy, procedure or practice in relation to any of the following?	
<input type="checkbox"/> Complaints <input type="checkbox"/> Eligibility criteria <input type="checkbox"/> KPI's <input checked="" type="checkbox"/> Service Uptake	
<input type="checkbox"/> User Satisfaction <input type="checkbox"/> Equality characteristics Other _____	
Which protected groups of people will be affected by the policy, procedure or practice? E.g. particular service users, staff, patients etc. Please tick the box if any of the following protected groups will be affected? Provide brief details about the nature of impact. Use, anecdotal qualitative or quantitative in-house information identified above both local and any regional and national research findings, surveys, reports, research interviews, minutes from focus groups, anecdotal evidence stated in organisational documents, other forms of engagement activities, pilot activity evaluations etc. If there are gaps in evidence state what you will do to close them.	

Age YES <input type="checkbox"/> NO <input type="checkbox"/>	Disability YES <input type="checkbox"/> NO <input type="checkbox"/>
Detail nature of impact	Detail nature of impact
Gender reassignment YES <input type="checkbox"/> NO <input type="checkbox"/>	Marriage and civil partnership YES <input type="checkbox"/> NO <input type="checkbox"/>
Detail nature of impact	Detail nature of impact
Pregnancy and maternity YES <input type="checkbox"/> NO <input type="checkbox"/>	Race YES <input type="checkbox"/> NO <input type="checkbox"/>
Detail nature of impact	Detail nature of impact

Religion and belief YES <input type="checkbox"/> NO <input type="checkbox"/>	Sex YES <input type="checkbox"/> NO <input type="checkbox"/>
Detail nature of impact	Detail nature of impact
Sexual orientation YES <input type="checkbox"/> NO <input type="checkbox"/>	Other
Detail nature of impact	Detail nature of impact

DETERMINING EQUALITY RELEVANCE OF THIS FUNCTION?

Does this function have Relevance to Equality & Human Rights?
YES <input type="checkbox"/> NO <input type="checkbox"/>
<i>Note: Public authorities need to consider all of their functions in order to determine which of them are relevant to the aims of the duty. Some functions will be relevant to most or all protected groups.</i>

PROPORTIONALITY - Based on the answers above what weighting would you ascribe to this function?		
		LOW Low relevance or Insufficient information/evidence to make a judgement.

APPENDIX B ABBREVIATIONS AND DEFINITIONS

Abbreviation	Meaning
People with lived experience	All people who use our services. This may include service users, their families and carers..
HM	Her Majesty
KMPT	Kent and Medway Partnership Trust
NHS	National Health Service
TWPEG	Trust Wide Patient Experience Group

APPENDIX C PERSONS/GROUPS INVOLVED IN THE DEVELOPMENT AND APPROVAL OF THIS DOCUMENT

TO BE UPDATED ONCE APPROVED AND CONSULTATION TAKES PLACE

-----PAGE BREAK-----

APPENDIX D FORMS

*Copies of all forms referred to within the document
Each form should appear as it would when used i.e. without “Appendix” reference or document headers and footers
please include cross reference to any existing documentation or highlight where any new documentation needs to be applied*

-----PAGE BREAK-----

Document Development Checklist

	DOCUMENT DEVELOPMENT CHECKLIST	Yes	No	Comments Including if not applicable
1.	Are the following pages fully completed?			
	a) Front page			
	b) Document Tracking Sheet			
	c) Summary of Changes			
2.	If more than 3 pages, is there a document summary			
3.	Are the reasons for developing the document clearly stated?			
4.	Are the Objectives of the document clearly defined?			
5.	Were all the relevant individuals, groups, stakeholders, disciplines consulted/involved in developing the document?			
6.	Does the policy address previously identified risks/incidents/complaints?			
7.	Are new patient information leaflets required?			
8.	Are the staff that should be using the document identified?			
9.	Are the patients/users to whom the document applies identified?			
10.	Is there a description of the circumstances where exceptions might be made?			
11.	Are all abbreviations described?			
12.	Can you confirm that this policy is not duplicating an existing policy?			
13.	Are pages and paragraphs numbered?			
14.	Was the document reviewed by independent experts prior to approval?			
15.	Does the document specify criteria for monitoring compliance?			
16.	Does the document identify clear targets?			
17.	Does the document define measurable outcomes that can be monitored?			