

# Patient Expert (PE) Survey findings 2012 – action plan update October 2014 (end Q2 2014/15)

Key: PIP = Public Involvement Programme, TA = Technology Appraisals team, PE = Patient Experts

<b>1 Exit questionnaires</b>						
No	Recommendation	Action	Who	Imp date	Review date	Status notes
1	<b>Develop Patient Expert exit questionnaire</b>	Use survey findings, and general PIP lay member exit questionnaire, as basis for questions	PIP/TA/lay participants	Q4 14/15	Q2 15/16	
		Implement questionnaire	PIP	Q115/16		
		Produce 6 monthly reports	PIP	Q215/16	Q4 15/16	
<b>2 Support before the meeting</b>						
No	Recommendation	Action	Who	Imp date	Review date	Status notes
2a	<b>Increase usage of Patient Expert ‘hints and tips’</b>	Send out with PE invitation	TA	Done		Done
		Encourage PE to read hints and tips by pre-meeting email or phone.	PIP	Done		Done
2b	<b>Increase PE awareness of number of people at the committee meeting</b>	Increased usage of PE hints and tips (as recommendation above)	PIP	Done		Done
		Check that all new PEs know the number of people attending the meeting by pre-meeting email or phone, and on the day (template).	PIP	Done		Done
<b>3 PIP support</b>						
No	Recommendation	Action	Who	Imp date	Review date	Status notes
	<b>Provide ‘light touch’ differentiated support to repeat PEs.</b>	Pre-meeting support by email, not phone, checking that PEs have all they require and whether they have any questions. Create template. Reflect in Standard Operating Procedure.	PIP	Done	Q1 15/16	
<b>4 Role of the chair</b>						
No	Recommendation	Action	Who	Imp date	Review date	Status notes
4a	<b>Inform the committee chairs and vice chairs how key their role is to the patient experts’ participation at committee.</b>	• Agree with TA	PIP/TA	Done		Done
		• TA to raise with Chairs/Vice Chairs, at quarterly meeting and roll out via lead Chair	PIP/TA	Done		Done
		• Ensure addressed appropriately in Chair/VC	PIP/TA	Done		Done

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		training/induction				
4b	<b>Committee chairs to informally introduce him/herself or be introduced to patient experts at the start of the meetings.</b>	<ul style="list-style-type: none"> <li>Agree with TA</li> </ul>	PIP/TA	Done		Done
		<ul style="list-style-type: none"> <li>TA to raise with Chairs/Vice Chairs, at quarterly meeting and roll out via lead Chair</li> </ul>	TA	Done		Done
		<ul style="list-style-type: none"> <li>PIP to suggest wording for TA to amend template Chairs' committee briefing notes</li> </ul>	PIP	Done		Done
		<ul style="list-style-type: none"> <li>Ensure addressed appropriately in Chair/VC training/induction</li> </ul>	PIP/TA	Done		Done
		<ul style="list-style-type: none"> <li>TA to remind Chairs, where appropriate</li> </ul>	TA	Done		Done
		<ul style="list-style-type: none"> <li>To be reviewed as part of Chairs' appraisal</li> </ul>	TA	Done		Done
4c	<b>Committee chairs to have a standard introduction at the beginning of committee briefly outlining the role of the experts (for the experts' and public gallery's benefit) to include:</b> 1. Stay for part one 2. No presentation required as we have their statements 3. Answer questions and participate in the discussion	<ul style="list-style-type: none"> <li>Agree with TA</li> </ul>	PIP/TA	Done		Done
		<ul style="list-style-type: none"> <li>Feed in to TA via PIP link</li> </ul>	PIP/TA	Done		Done
		<ul style="list-style-type: none"> <li>TA to raise with Chairs/VCS, at quarterly meeting and roll out via lead Chair</li> </ul>	PIP/TA	Done		Done
		<ul style="list-style-type: none"> <li>PIP to suggest wording for TA to amend template Chairs' committee briefing notes – 2 sentences based on Process Guide wording</li> </ul>	PIP/TA	Done		Done
		<ul style="list-style-type: none"> <li>Ensure addressed appropriately in Chair/Vice Chair training/induction</li> </ul>	PIP/TA	Done		Done
4d	<b>Include feedback on the role of the chair in the patient expert exit questionnaire.</b>	Links with recommendation 1 above	PIP	Q4 14/15	Q2 15/16	
<b>5 Clarity about the patient expert role and purpose</b>						
No	Recommendation	Action	Who	Imp date	Review date	Status notes
5a	<b>Committee chairs to have a standard introduction at the beginning of committee briefly outlining the role of the experts (for the experts and public gallery's benefit) to include:</b> <ul style="list-style-type: none"> <li>Stay for part one</li> <li>No presentation required as we have their</li> </ul>	See 4c	See 4c	Done		Done

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	<b>statements</b> <ul style="list-style-type: none"><li>• Answer questions and participate in the discussion</li></ul>					
5b	<b>Update the hints and tips for patient experts and increase awareness.</b>	See 2a and 2 b	PIP/TA	Done		
5c	<b>Review the hints and tips for patient experts with patient experts and organisations</b>	As recommendation	PIP/TA	Q3 14/15		
5d	<b>Issue updated version of hints and tips when the new process guide is published.</b>	As recommendation	PIP/TA	Q4 14/15		
5e	<b>Reiterate the role of the patient expert in contact before the committee meeting</b>	• Standard Operating Procedure	PIP	Done		Done
		• Email template	PIP	Done		Done
		• Phone call prompt sheet	PIP	Done		Done
5f	<b>Clarify the role of patient experts at the second committee meeting with TA.</b>	• Agree with TA	PIP/TA	Done		Done
		• Feed in to TA via PIP link	PIP/TA	Done		Done
		• PIP to suggest wording for TA to amend committee briefing notes template: <ul style="list-style-type: none"><li>○ We may have received additional evidence</li><li>○ Also to clarify consultation comments from them, or their perspective</li></ul>	PIP/TA	Done		Done
5g	<b>Give more information to patient experts about their role before second or subsequent meetings.</b>	• Template email	PIP/TA	Done		Done
		• Standard Operating Procedures	PIP/TA	Done		Done
		• Next edition of patient expert hints and tips	PIP/TA	Done		Done
<b>6</b> <i>Paperwork before the meeting</i>						
<b>sect page</b>	<b>Recommendation</b>	<b>Action</b>	<b>Who</b>	<b>Imp date</b>	<b>Review date</b>	<b>Status notes</b>
6a	<b>Update the patient expert invitation letter to make clearer.</b>	TA to draft and PIP to feed into new updated invite	PIP/TA	Done		Done
6b	<b>Send out the hints and tips for patient expert with the invitation to participate.</b>	See 2a above	TA	Done		Done
6c	<b>Publish more information on the NICE website specifically written to support patient experts and patient carer</b>	• Add hints and tips for patient experts to the website	PIP	Done		Done
		• Write new version factsheet for patient and	PIP	Done		Done

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	<b>organisations and link to it from the NICE correspondence.</b>	carer organisations on participating in TAs to replace 'a guide for patient and carer organisations'				
		• Review by TA the editors	PIP/TA/editors	Done		Done
		• Write a factsheet on scoping for TAs	PIP	Done		Done
		• Review by TA and editors	PIP/TA/editors	Done		Done
		• Publish on the website	PIP	Done		Done
		• Include links to website documents from NICE correspondence	PIP/TA	Done		Done
6d	<b>Consider plain English titles of the attachments which describe their content for invitations to participate and patient expert invitations to make the content clearer.</b>	• Discuss the naming with TA (including summary and procedure to include timelines)	PIP/TA	Q4 13/14		This is ready to be implemented to coincide with the new process guide in Q3 2014/2015
		• Resolve the issue of two declarations forms (for PEs) – should be resolved with the new TA statement templates.	PIP/TA	Q4 13/14		
		• Discuss terminology for submissions and statements with TA.	PIP/TA	Q4 13/14		
		• PIP to suggest alternative names to TA	PIP/TA	Q4 13/14		
6e	<b>Review the number of attachments to invitations to participate and patient expert invitations.</b>	• Discuss with TA lead (linked to 6d)	PIP/TA	Q4 13/14		This is ready to be implemented to coincide with the new process guide in Q3 2014/2015
6f	<b>Produce a factsheet on documents and timelines for patient organisations</b>	See 6c (included in the document for patient and carer organisations)		Done		Done
6g	<b>Explore including key milestones on the website (e.g. nominations, CA&amp;U and submission deadline) which could be linked to emails</b>	• This could be done by including a few extra fields on the TA page and by including the summary page with the other key documents on the topic webpage (then this could be linked instead of an attachment). Discuss with TA.	PIP/TA			This was explored but found unfeasible
		• TA to clearly label summary document with timelines when NICE docs is implemented	TA	Done		Done
		• Extract the timelines from the process guide – or develop a simplified version and publish that on the website as part of the PIP information – develop as PIP Masterclass	PIP	Done		Masterclass materials have been produced and the publication of

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		support material				the timelines will coincide with the new process guide in Q3 2014/2015
6h	<b>Send patient experts committee papers in line with the process guide so that they have enough time to read the documents</b>	<ul style="list-style-type: none"> <li>Flag with TA.</li> </ul>	PIP/TA	Done		Done
<b>7 Patient expert statement/submission</b>						
No	Recommendation	Action	Who	Imp date	Review date	Status notes
7a	<b>Increase support to patient organisations and experts with their statements</b>	<ul style="list-style-type: none"> <li>Develop new TA templates</li> </ul>	PIP/TA	Done		Done
		<ul style="list-style-type: none"> <li>Give support on submissions and statements in the PIP masterclasses</li> </ul>	PIP	Done	annually	Annually, as required
		<ul style="list-style-type: none"> <li>Publish support from masterclasses on the website</li> </ul>	PIP			In hand
		<ul style="list-style-type: none"> <li>Produce a briefing note to accompany new submission template (if necessary)</li> </ul>	PIP/TA	Carried forward		Carried forward
7b	<b>Consider how we can increase help to nominating organisations support their nominees with their personal statements.</b>	<ul style="list-style-type: none"> <li>Use the exit survey to help find out how we could do this (see 1)</li> </ul>	PIP (see 1)	(see 1)		
<b>8 Role of the lay lead</b>						
No	Recommendation	Action	Who	Imp date	Review date	Status notes
8a	<b>Clarify the lay lead role.</b>	<ul style="list-style-type: none"> <li>Include and clarify the lay lead role in the hints and tips information</li> </ul>	PIP/TA	Done		Done
		<ul style="list-style-type: none"> <li>Send out the hints and tips to patient experts before the committee meeting.</li> </ul>	PIP/TA	Done		Done
8b	<b>Clarify the relationship and difference between the roles of the patient expert and the lay members and lay lead to PE and committee.</b>	<ul style="list-style-type: none"> <li>The lay lead role has been clarified at TA committee inductions</li> <li>The respective roles for lay lead and patient expert are covered in the new hints and tips</li> </ul>	PIP/TA PIP/TA	Done Done		Done
8c	<b>Increase awareness of lay lead role to patient experts.</b>	<ul style="list-style-type: none"> <li>See 8a</li> </ul>	PIP	Done		Done
		<ul style="list-style-type: none"> <li>Include in pre-meeting phone call to PEs (reflect in Standard Operating Procedure and crib sheet)</li> </ul>	PIP	Done		Done
8d	<b>Consider whether the lay lead could help</b>	<ul style="list-style-type: none"> <li>PIP to review with lay members including</li> </ul>	PIP	Q4		Include in standing

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	make the patient experts feel less intimidated at the meeting by meeting them at the beginning of the meeting	practicalities.		14/15		lay members' day afternoon session
8e	Draw up a list of possible questions for patient experts that so that at least one relevant question will always be asked.	• Draft questions which could be asked by the lay lead (or lay members). Committee Chair to ensure Lay Lead is encouraged to ask Questions of the patient experts.	PIP/TA	Done		Done
		• Roll out through discussion with lay members	PIP/TA	Done		Done
9 Understanding the slide sets						
No	Recommendation	Action	Who	Imp date	Review date	Status notes
9	Explore options for increasing understanding of the committee slide sets.	Consider:	PIP/TA	Q4 13/14		This is ready to be implemented to coincide with the new process guide in Q3 2014/2015
		• Less information on each slide	PIP/TA	Q1 14/15		
		• Plainer English	PIP/TA	Q1 14/15		
		• Cutting down on acronyms unless they are all explained	PIP/TA	Q1 14/15		
		• Making the clinical presentation be more lay friendly possibly by including the lay member in more of the presentation?	PIP/TA	Q1 14/15		
		• Breaking up long presentations by not just reading them verbatim or by including the lay lead more.	PIP/TA	Q1 14/15		
		• Adapting some of the more complex statistical data to more visual graphics - pie charts and bar charts for alternative ways of formatting and illustrating information, wherever possible	PIP/TA	Q1 14/15		
		• TA to explore redesigning committee meeting slide templates – separate out 'the condition', impact and patient issues, from clinical data?	TA	Q1 14/15		
	• Colour copies for ease of reading	PIP/TA	Q4 13/14		Not feasible as standard	
10 Understanding the committee discussions						

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10	Encourage other committee members, including the lay lead to ask relevant questions related to patient experience	See 8				Ongoing
11 Understanding technical terms/jargon						
No	Recommendation	Action	Who	Imp date	Review date	Status notes
11a	Review the forms and paperwork that the patient experts and patient organisations receive to ensure that they are in plain English	• Check with TA whether editors have checked all the patient correspondence templates	PIP/TA	Q4 13/14		This is ready to be implemented to coincide with the new process guide in Q3 2014/2015
		• If not, TA to send to editors	TA/editor	Q1 14/15		
		• Roll out	TA	Q1 14/15		
11b	Provide a glossary	• Increase awareness of glossary in the organisational fact sheet	PIP	Done		The new NICE website highlights words in the text and links them to a glossary.
		• Put a link to the online glossary in TA patient correspondence templates	PIP/TA	Done		
		• Put a PDF version of the TA glossary on the website and link to it	PIP	Done		
		• For concepts rather than understanding what terms mean, there are there are other resources such as training and masterclasses.	PIP	annual		Done
12 Closing statements						
No	Recommendation	Action	Who	Imp date	Review date	Status notes
12	Encourage chairs to give patient experts the opportunity for a closing statement which may incorporate any issues that the PE thinks relevant but have not had the opportunity to raise.	See 4				Done
13 Expenses						

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13a	<b>Review the long help guide sent to people</b>		Done	Done		Done
13b	<b>Highlight the offer of a paper copy to one off attendees</b>	• Discuss with TA	PIP/TA	Done		Done
		• PIP to investigate use of paper copies in other NICE teams and committees	PIP	Done		Done
		• Amend documentation (Hints and Tips, and TA letters) accordingly	PIP/TA	Done		Done
13c	<b>Produce a plain English version of the expenses policy for patients and the public.</b>	• Approach finance and editors	PIP/finance/editors	Q2 14/15		
13d	<b>Highlight the offer of a helpline to those who need it.</b>	• Discuss with TA and amend documentation accordingly	PIP/TA	Done		Done
13e	<b>Explore hands on training via PIN to patient experts who work for organisations and come to several NICE events</b>	• Discuss with finance	PIP/finance	Done		Online tutorial on the NICE website and sent out to all patient experts
13f	<b>Offer 'one off' patient experts the alternative paper system on the day – this was suggested by patient experts.</b>	• Discuss with TA (see 13b)	PIP/TA	Done		Offer of paper system in place and PIP documentation will be updated to coincide with process guide.
		• Amend documentation accordingly	PIP/TA	Done		