

Patient Leaders Peer Support Group

Wednesday 6 April 2016 12:30pm – 2:30pm
 Leafield Clinic, 107-109 King Ln, Leeds LS17 5BP
Minutes of Meeting

Membership	Initials	CCG	Role	Present	Apologies
Pat Newdall	PN	North	Breast Diagnostic project, Gynaecology, PAG (North)	✓	
Steven Elsmere	SE	West	Community beds project	✓	
Sandra Eames	SE	West	End of life, Patient leader website development, Pharmaceutical project		
Trish Mckinney	TM	West	Patient empowerment project, Childhood obesity project, Care Homes, PAG (West), PRG	✓	
Bob McDougal	BM	West	Cardiovascular disease project, Right care		
Sue Watson	SW	North	Chronic pain project, Endoscopy		
Paul Hazelgrave	PH	South & East	Chronic pain project	✓	
Lynda Burt	LB	West	PAG (West), PRG, Breast Diagnostic		
Phil Monk	PM	West	Diabetes project, Right care project		✓
Alison Potts	AP	?	Discharge to assess project		
Tony Sykes	TS	West	Discharge to assess project, Right care project, Community beds		
Lesley Sterling-Baxter	LSB	North	Healthwatch		
Moneer Sharif	MS	West	Healthwatch		
Sally Morgan	SM	West	Healthwatch, PAG (West)		
Les France	LF	?	none		
Pat Nelthorpe	PNT	West	Gynaecology		
Robert Turner	RT	West	PAG (West), PRG		
Linda Birch	LBir	West	none		
Margaret Wilkinson	MW	North	PAG (North)	✓	
Leanne Winfield	LW	West	LYPFT		✓
Brian Kemp	BK	North	PRG	✓	
Kevin Bray	KB	West	PRG, PAG (West)	✓	
Simon Copland	SC	West	PRG		
Logie Kelman	LK	West	PRG, PAG (West)		
Anne Suttle-Burton	ASB	West	PRG		
Gavin McNaughton	GM	West	Primary care		
AZ	AZ	North	PPG		
Barbara Naylor	BN	West	PPG - Rawdon		✓
Freda Irvine	FI	West	PPG - Rawdon		✓
Barrie Dyer	BD	North	PPG - Church View	✓	
Danny Benn	DB	West	PPG – Ireland Wood, LCH	✓	
Ronnie Hinscliffe	RH	?	PPG -		✓
Chris Bridle (facilitator)	CB	West	NHS Leeds West CCG Engagement Lead	✓	
Guests					
Jessica Drinkwater	JD	North	GP for Patient Participation	✓	
Catherine Bowhill	CB	North	Comms and engagement officer	✓	

Item	Description										
1.0	<p data-bbox="228 199 616 230">Patient Leaders Pre-meet</p> <p data-bbox="228 271 1326 367">Following the pre-meet the patient leaders raised a number of issues around patient participation groups (PPGs). PPGs are groups of patients at practices who come together to help improve the practice.</p> <p data-bbox="228 405 1326 535">There were a number of themes that were identified by the group. Patients in different practices appear to be experiencing similar challenges. Below I have tried to summarise the themes captured in the meeting and outline potential interventions suggested by patients at the group.</p> <table border="1" data-bbox="228 568 1321 2063"> <thead> <tr> <th data-bbox="228 568 778 674">Challenges/themes</th> <th data-bbox="778 568 1321 674">Potential solutions</th> </tr> </thead> <tbody> <tr> <td data-bbox="228 674 778 987"> <p data-bbox="244 680 727 875">1. Huge variation in the quality and effectiveness of PPGs across the city. 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<p>get involved (peer review, recruitment etc). Is there something we can learn from hospital doctors who appear to be more signed up to the engagement approach</p>	
<p>5. How do we balance the recognised job of GPs (caring for patients) with their responsibility to engage and involve.</p>	<ul style="list-style-type: none"> • Sharing the responsibility of PPGs between the practice, patients and the CCG • CCG to provide more support for practices with regards to engagement and involvement
<p>6. Resources for practices are a big issue. Concerns about resources for engaging with and involving the public</p>	<ul style="list-style-type: none"> • Work closely with local voluntary organisations to support engagement • Ask PPG members to get more involved in the work (chair the group, get involved in the engagement activities) • Outline the support that the CCG can offer in regards to PPGs
<p>7. Skills, knowledge and experience of engagement amongst practice staff is varied. Can we expect practice staff to run effective and meaningful patient groups without this?</p>	<ul style="list-style-type: none"> • Patient led training for practice staff could help develop their understanding of how to run effective and meaningful PPGs • Standards for PPGs could help practice measure success
<p>8. Recruiting patients to PPGs is a challenge. Again this links to resources available in GP practices</p>	<ul style="list-style-type: none"> • Use existing resources in practice like mjog • Use local voluntary organisations to promote the PPG • Using social media
<p>9. Making patient groups accessible is a challenge for practices. How can we support people with protected characteristics or from vulnerable communities to get involved? In the absence of diversity how can patient leader consider the needs and preferences of specific groups in the community?</p>	<ul style="list-style-type: none"> • Accessible information standards tells organisations how they should make sure that disabled patients receive information in formats that they can understand and receive appropriate support to help them to communicate. • PPGs can understand more about the needs and preferences of diverse groups by looking at their practice profiles and national GP survey results. • If PPG recognise a gap in their knowledge they could invite a local voluntary sector organisation to attend the group and outline the challenges to a specific community
<p>10. There don't appear to be any standards for engagement in GP practices. How do we know if PPGs are effective, successful and meaningful? Will this look the same in all GP practices?</p>	<ul style="list-style-type: none"> • Involve PPG members and practice staff in developing an agreed set of standards for PPGs. The standards should outline some basic principles that make PPGs effective and meaningful • Consider asking the PPG to assess their practice against the standards

	<ul style="list-style-type: none"> • Consider asking PPG members from other practices to assess against the standards 	
<p>11. How can we build and develop trust between patients and clinicians so that they can work more effectively together. It was suggested that some GPs were 'afraid' of PPGs and some PPG members felt that their PPG was not taken seriously.</p>	<ul style="list-style-type: none"> • The agenda for the meeting should be influenced by patients. • Meetings should be attended by clinicians so that they can listen to the views of patient directly and share the challenges faced by the practice. This dialogue is important which is why virtual groups sometimes are not effective. • Minutes should be available on the website • Involve patients more activity at the practice. This might include peer review, recruitment of staff and assessment against a set of standards. • Patient attending PPGs should be encouraged to attend training to outline their role 	
<p>12. How can we improve communication between NHS England, CCGs and PPGs. Are we missing opportunities to involve PPGs in important pieces of work because practices are the gatekeepers of information? How can we ensure that information gets to patients.</p>	<ul style="list-style-type: none"> • We could ask for each PPG to have a nominated patient who would receive communications from the CCG. This would help ensure that PPG members received information and take pressure off the practice manager • The CCG could send out a list of agenda items that PPGs could have at their meeting. This would ensure that the group were aware of recent developments and would avoid discussion become stale. • Encourage PPG members to sign up to the CCG network. This would ensure that individuals received information about engagement directly from the CCG without having to rely on the practice manager to disseminate information • Where possible representatives from the CCG could visit PPGs 	
<p>It was pointed out to patients that having a PPG is a mandatory requirement for practices.</p> <p>ACTION: CB to share useful resources for PPG members</p> <ul style="list-style-type: none"> • The results of your GP practice survey can be found here: https://gp-patient.co.uk/ This resources allows you to see what patients have said about your practice. It also allows you to compare your practice with other local practices. NOTE please be aware that the results are only as good as the methods – in some cases very few patients have filled this in and participants are often not representative of the people living in your area. The equality monitoring breakdown might help you identify people in the community whose voice is not being heard by the practice 		

CB

	<ul style="list-style-type: none"> You can view your practice profile here: http://fingertips.phe.org.uk/profile/general-practice this gives you a good understanding of the different communities that live in your area. This citywide toolkit for PPGs is a little out of date but it still provides some useful tips and resources for running an effective PPG: http://www.leedswestccg.nhs.uk/content/uploads/2015/12/PPDES-Toolkit-FINAL.pdf The National Association of Patient Participation offers lots of useful information and guidance on PPGs: http://www.napp.org.uk/ There is lots of other useful information on our patient leader page here: http://www.leedswestccg.nhs.uk/get-involved/how/patient-leader-programme/ <p>ACTION: CB to speak with engagement, comms and primary care colleagues at the other CCGs to discuss how we can take these issues forward. Will bring a list of suggested interventions at the next meeting</p>	CB
2.0	<p>Minutes of the last meeting Did not review the minutes of the last meeting</p>	
3.0	<p>Update on the programme:</p> <ul style="list-style-type: none"> Some stats... <ul style="list-style-type: none"> Currently 40 patient leaders on the programme We have run eleven patient leader training sessions We have run ten peer support groups 85 people from across Leeds have attended the patient leader training Patient leaders have written four blogs Patient leaders sit on 19 different commissioning steering groups Patient leader volunteer over 100 hours every month! Patient leader programme The programme continues to be popular with patients and is receiving recognition from other CCGs and national organisations. In April CB and one of the patient leaders will be attending a national event to share good practice around patient leadership. Training Five of the nine sessions have now been developed and are being delivered on a rolling basis. The last four sessions are on hold currently. The training continues to evaluate very well. People can find out more about the training here: http://www.leedswestccg.nhs.uk/get-involved/how/patient-leader-programme/patient-leader-training/ Patient of leeds concept Getting involved in the local NHS is complicated. You need to know which CCG you belong, what you want to do and which of the many organisations you need to search for. 'Patients of Leeds' is an early concept that is designed to make it easier for people in Leeds to get involved in local healthcare decision-making. At the next Peoples Voices Group (a meeting of engagement leads in Leeds) we will be looking at how we can work together better to support engagement in the city. This project is currently on hold. Patient leader opportunities (on hold, with one exception) Two patient leaders needed for the primary care work (Leeds West CCG only) 	

	<ul style="list-style-type: none"> • Website development <p>On hold</p>	
4.0	<p>AOB</p> <p>None</p>	
	<p>Date and time of next meeting</p> <p>The group will meet every 6 weeks. Following feedback from the group the meetings will be held alternately on Mon afternoons and Tues evenings. This will help make the meeting more accessible to people who have commitments during the day.</p> <p>The next meeting will be on: Tuesday 10 May 2016 NHS Leeds West CCG, Suites 2-4, Wira House, Wira Business Park, West Park Ring Road, Leeds LS16 6EB Directions: http://www.leedswestccg.nhs.uk/content/uploads/2014/12/WIRA-Map-Final.pdf</p> <p>6pm - 6:30pm pre meet for patient leaders only 6:30pm – 8pm main meeting</p> <p>Agenda to be sent out one week prior to the meeting.</p>	

Action log

You said	We did
Patient leader training not accessible to people who work in the week	One quarter of future training sessions will be run at the weekend
Not enough groupwork in the patient leader training sessions	More groupwork included in future training sessions
Some staff are not aware of the patient leader programme or how that can support patient leaders	We have run two learning lunches for staff. There were attended by senior commissioners and patient leaders. Will continue to run these sessions.
Some people on the group are not comfortable with the term 'patient leader'	When we evaluated the programme in July 2015 we asked people to tell us their opinion. Over 60% said they were happy with the term. We will review the term at the next evaluation
You need to add the time period when asking for patient leaders to tell us how many hours they have committed	Have organised for our admin team to collect hours every month. This is optional.
We would like to see what the patient leader webpage will look like?	Patient leaders are involved in developing the webpage
Why have patient leaders been excluded from the community bed discussions?	Dialogue is back open between the group and patient leaders
Why can't we claim expenses for printing?	Expenses policy being reviewed
Can you share details of involvement at the NHS trusts in Leeds?	Shared details of NHS trust membership schemes
Can you run patient leader learning lunches at the other CCGs?	We have offered to run learning lunches at other CCGs
Can we have a guide for patient leaders?	In development
We are concerned that engagement and involvement is not included in the evaluation of the care homes work	This was highlighted in the meeting
We are concerned that the chronic pain interactive tool is not available on PCs	Following feedback from patient leaders the CCG has made a small contribution to the organisation who will now develop an app for PCs.
Can you include something in the social media training about using tablet reading tools?	
CB to discuss the possibility of a citywide PPG event	
CB to carry out a second evaluation of the programme in the summer 2016. This will include a question about the title given to patient leaders.	
CB to develop a draft volunteering policy and share with patient leaders	
CB to chase up progress on the SPA project and report back to patient leaders	