

Patient Leaders Peer Support Group

Tuesday 10 May 2016 6pm – 8pm

NHS Leeds West CCG, Suites 2-4, Wira House, West Park Ring Road, Leeds LS16 6EB

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 -	✓	
Sharon Agyemang	SA	South & East	Children's Asthma		✓
Chris Bridle (facilitator)	CB	West	NHS Leeds West CCG Engagement Lead	✓	
Guests					

Item	Description
1.0	<p data-bbox="228 264 1134 300">Following the pre-meet the patient leaders raised a number of issues:</p> <ul style="list-style-type: none"> <li data-bbox="228 333 657 369"> <p data-bbox="228 333 657 369">• Influencing service change</p> <p data-bbox="228 369 1310 770">The group discussed how we can support improvement in services that we have concerns about. We talked about the importance of being able to step back from your personal experiences of using services. We also talked about the importance of not relying on hearsay or assumptions. CB advised that individual concerns or complaints should be directed to the service manager or a complaints service such as the Patient Advice and Liaison Service. We used the commissioning cycle as a way of exploring how services can be improved. It was suggested by CB that changes to services need to be evidence based; in the case of poor patient experience, there needs to be evidence that multiple people are experiencing difficulties with the service. This evidence can come from complaints, the friends and families tests and surveys. This information can help you argue a case for change.</p> <li data-bbox="228 808 1323 875"> <p data-bbox="228 808 1323 875">• patient participation groups (PPGs are groups of patients at practices who come together to help improve the practice)</p> <p data-bbox="228 875 1310 1178">One patient leader expressed some frustration about his newly formed PPG. He explained that there appeared to be no strategic direction for the group and it appeared to be a 'tick-box exercise'. We discussed how patients can agree meaningful actions for the group. CB suggested using wider patient feedback as a way of identifying issues at the practice. CB suggested that PPG members should try and avoid sharing their own opinions and experiences because the group is unlikely to represent the wider population. The actions of the PPG should not be driven by a minority group of people. CB pointed out that there are some useful tools available for understanding the experience of patients using the practice:</p> <ul style="list-style-type: none"> <li data-bbox="256 1178 727 1214">○ The national GP practice survey <li data-bbox="256 1214 703 1249">○ NHS England practice profiles <li data-bbox="256 1249 488 1285">○ Local surveys <li data-bbox="256 1285 962 1321">○ Complaints and compliments made at the practice <p data-bbox="228 1321 1286 1379">This evidence can help the group identify trends and themes. These themes can make up actions for the group.</p> <li data-bbox="228 1417 1038 1453"> <p data-bbox="228 1417 1038 1453">• Patient leadership on strategic commissioning groups</p> <p data-bbox="228 1453 1310 1615">The group discussed the challenges associated with a complex service change. Concerns were raised that decisions being made at the group were based on professional's ability to put forward a case rather than patient need. CB acknowledged the challenges in this project and suggested that the patient leaders involved focussed on the role as patient leaders:</p> <ul style="list-style-type: none"> <li data-bbox="256 1615 1238 1682">○ Does the project understand the needs and preferences of patients and carers involved in the service? <li data-bbox="256 1682 1075 1718">○ If it doesn't then an argument could be made to re-engage. <li data-bbox="256 1718 1161 1753">○ Has the projects acted on the feedback from patients and carers? <li data-bbox="256 1753 507 1789">○ If not, why not? <p data-bbox="228 1789 1182 1848">CB offered to attend the group to support the patient leaders to ask these questions.</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 • 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/ 	
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 50 patient leaders on the programme ○ We have run twelve patient leader training sessions ○ We have run eleven peer support groups ○ 93 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 May CB and one of the patient leaders will be attending a national event to deliver a poster presentation on the Leeds patient leadership programme • 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 	

	<p>at how we can work together better to support engagement in the city. This project is currently on hold.</p> <ul style="list-style-type: none"> • Patient leader opportunities (on hold, with one exception) Two patient leaders needed for the primary care work (Leeds West CCG only) • Website development On hold 	
4.0	<p>AOB 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: Monday 20 June 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>12:30pm - 1pm pre meet for patient leaders only 1pm – 2:30pm 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	