

Patient Leaders Peer Support Group

Wednesday 21 September 2016 12:30pm – 2:30pm

Wira House, Leeds, LS16 6EB

Notes 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	PEP, 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	S&E	Chronic pain project		
Lynda Burt	LB	West	PAG (West), PRG, Breast Diagnostic		
Phil Monk	PM	West	Diabetes project, Right care project		
Alison Potts	AP	S&E	Discharge to assess project		
Tony Sykes	TS	West	D2A project, Right care project, Comm 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 – Rutland Lodge		✓
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	West	PPG – Abbey Grange		
Savi Tynedale-Biscoe	STB	North	PAG		✓
Beverley Kite	BVK	North	PPG		✓
Andrew Stenson	AS	West	PPG, primary care	✓	
Diana Al-Saadi	DAS	West	?		✓
Sylvia Landells	SL	West	?		✓
Shaheen Akhtar	SA	West	?	✓	
Chris Bridle (facilitator)	CB	West	NHS Leeds West CCG Engagement Lead	✓	
Guests					

Patient leaders took the opportunity to discuss their involvement in individual projects during the pre-meet.

Following the pre-meet the group discussed the following topics:

Challenges/themes	Potential solutions
<p>1. Feeling assured that the engagement taking place for a project is robust. We discussed how one person on a group can champion the views of the wider community and how to avoid becoming a 'token' patient who 'signs off' change.</p>	<ul style="list-style-type: none"> • Be aware of the engagement cycle and that engagement should play a part in each stage. • Consider the size and scale of the change and capacity of the organisation. Does the amount of engagement reflect this? • Ask for support from the engagement team, from the Patient Assurance Group or other patient champions. • Focus on asking for evidence of engagement with the wider public. What did the data show, where are the gaps and how is the data being used to drive the project • Consider asking how the voice of the wider public will be used at each stage of the cycle • If developing an 'app' consider using a user group to test the app at different stages of development • Ask to use our partners in the voluntary sector to understand the impact of the change on different groups in the community. Consider the gaps and how they will be addressed • Consider using person 'personas' that reflect the wider community, ask the commissioners to demonstrate how these personas will be affected by the change.
<p>2. How to challenge when you feel the minutes of a meeting do not reflect the content. This turned into a wider discussion about supporting staff who have a patient champion on their group</p>	<ul style="list-style-type: none"> • Consider sharing your version of events directly with the chair of the group. • Consider asking a member of the engagement team to support you to challenge the minutes. • CB explained that there is guidance for professionals on how to support a patient champion. • CB explained that patient champions will only be allocated to a group once the lead member of staff has completed a short training session on patient leadership. • Ongoing training and awareness-raising with staff is essential if the programme is to be successful.
<p>3. Concerns were raised about issues in the pathology department at LTHT.</p>	<ul style="list-style-type: none"> • A member of staff from LTHT was at the meeting. They explained the issue and told the group that staff were working through the night to resolve it asap.
<p>4. The group discussed Patient Participation Groups at GP practices</p>	<ul style="list-style-type: none"> • KB told the group that their PPG has asked if patients could be involved in the recruitment of staff. The PPG has agreed to this in principle. ACTION CB to look at whether the CCG can support this approach by giving patient champions access to recruitment training. • ASB shared her experience of being involved in the patient group at Leigh View Medical Centre. She told the group that the staff at practice has been very support of the group. The group has created lots of opportunities for patients to get involved in: <ul style="list-style-type: none"> ○ Chair aerobics ○ Lunch clubs ○ Craft afternoons <p>The group have also been involved in carrying out survey about online services and extended hours.</p>

	<p>ASB explained that the Patient Empowerment Project did not have much involvement with the group. ASB acknowledged that the existing groups only targeted people who regularly used the practice. She recognised that the role of the group is to serve the whole population and she has arranged to engage people who don't regularly use the practice through the flu clinic. ACTION: CB to liaise with PEP about their involvement at the practice</p> <ul style="list-style-type: none"> • SW also shared her experience of being involved in her PPG. • SA was interested in setting up a group at her practice to support people with Coeliac disease. ACTION: CB to look into support for SA
<p>5. The group discussed barriers to involvement in particular DBS checks</p>	<ul style="list-style-type: none"> • TM explained that DBS checks are free for volunteers.
<p>6. CB outlined the 'medications for minor conditions' engagement. He explained that treatments for minor conditions like coughs and colds were often prescribed when they could be bought over the counter at a fraction of the cost. The group discussed this</p>	<ul style="list-style-type: none"> • The group were surprised at the cost of prescribing for common conditions (over £2 million a year in Leeds for paracetamol). • The group raised concerns that GP's ceasing this type of prescribing would impact most on families with very low income. They suggested that the engagement should include this vulnerable group and that GPs should be given the freedom to prescribe when they thought it was appropriate. • The group also raised concerns that as people self-care more there may be reduced opportunities from GP to pick up on health problems at an early, treatable stage. We discussed the importance of health campaigns like 'got a cough, get a check' to ensure that people had the information to make informed choices. • The group asked where the money saved would go and they suggest that some of this should go into education.

Date and time of next meeting

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.

The next meeting will be on:

Monday 7 November 2016

Armley Medical Centre, 95 Town St, Leeds LS12 3HD

Directions:

<http://www.armleymedicalpractice.co.uk/contact1.aspx>

12:30pm - 1:00pm

pre meet for patient leaders only

1:00pm – 2:30pm

main meeting

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. In 2016 our evaluation showed support for renaming 'patient leaders', volunteers.
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?	The expenses forms have been updated and volunteers can now claim for printing at home* <small>*terms and conditions apply</small>
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	This event has been set up and will run in Sept 2016
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.	Evaluation can be accessed here: http://www.leedswestccg.nhs.uk/content/uploads/2015/07/PL-evaluation-report-2016.pdf
CB to develop a draft volunteering policy and share with patient leaders	Discussions are taking place to develop a citywide volunteering policy and accompanying principles
CB to chase up progress on the SPA project and report back to patient leaders	
CB to look at whether the CCG can support PPG involvement in recruitment by giving patient champions access to recruitment training.	
CB to liaise with PEP project re their involvement at Leigh View Medical Centre	
CB to liaise with PEP re support for SA in setting up a group for people with Coeliac disease	