

## Patient Leaders Peer Support Group

Monday 20 June 2016 12:30pm – 2:30pm

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 Diag 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	D2A project, Right care, 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 -		
Andrew Stenson	AS	West	PPG, interview		✓
Chris Bridle (facilitator)	CB	West	NHS Leeds West CCG Engagement Lead	✓	
<b>Guests</b>					
Sayed Loonat	SL	LTHT	Patient Experience Team	✓	
Rose Westhead	RW	West CCG	Engagement Officer	✓	

Item	Description
1.0	<p><b>Patient Leaders Pre-meet</b></p> <p>Patient leaders met without staff to discuss the challenges and opportunities around being a patient leader.</p>
2.0	<p><b>Main meeting</b></p> <p>Following the pre-meet the patient leaders shared the key issues for them in their project or PPG. The following themes emerged:</p> <ul style="list-style-type: none"> <li>• <i>What is the role of patient leader in addressing NHS waste?</i></li> <li>• <i>How can patient leaders work more closely with local voluntary, community and faith sector services?</i></li> <li>• <i>How can we share best practice about PPGs?</i></li> <li>• <i>How do patients feel assured that the engagement around maternity services for women with learning disabilities is robust?</i></li> <li>• <i>How do we support diverse communities to access health information?</i></li> <li>• <i>How can patient leaders get involved in the procurement process?</i></li> <li>• <i>What's the difference between evidence/data and hearsay?</i></li> <li>• <i>How much do patient leaders need to get involved in the wider aspects of commissioning projects (such as finance)?</i></li> <li>• <i>How do we understand the needs and preferences of different cultures?</i></li> </ul> <p>The group explored a number of these issues:</p> <p><b>1. How do patients feel assured that the engagement around maternity services for people with learning disabilities is robust</b></p> <p>One of the patient leaders shared a progress report a progress report on the 'women with learning disabilities' workstream in the maternity strategy. The group reviewed the document and some concerns were raised about assurance around the engagement for this piece of work. The patient leader wanted support from the other people on the group so that they could ask the right questions to understand if the engagement process was 'fit for purpose'. The group discussed what they needed to feel assured that engagement was robust. They agreed that there were a number of things which help them decide if the engagement is appropriate:</p> <ul style="list-style-type: none"> <li>• The number of people the engagement will affect</li> <li>• The size and scope of the change</li> <li>• Controversial issues</li> <li>• The impact on service users</li> <li>• The impact on people from easily ignored groups</li> <li>• Comparison to other similar engagements across the country (best practice)</li> <li>• Timescales for the project</li> </ul> <p>The group agreed that the progress report did not make it easy to decide if the engagement was robust. The group raised the following concerns:</p> <ul style="list-style-type: none"> <li>• Is four people a large enough sample size to understand the needs of women with learning disability?</li> <li>• What literature has been used to engage with this community? (accessible information standards)</li> <li>• Have other CCGs done something similar with this community?</li> <li>• There is a wide spectrum of learning disabilities, does this engagement consider people with different levels/types of learning disability?</li> <li>• How have the voluntary, community and faith sector been involved in the engagement?</li> </ul> <p>It was also pointed out that the report was sent out very late which made it difficult to fully digest the information before the meeting.</p>

	<p>At the end of the discussion the patient leader told the group that they felt more confident in what questions they could ask in future that would help them feel assured about the engagement process.</p> <p><a href="#">Maternity Strategy for Leeds</a></p> <p><b>2. How much do patient leaders need to get involved in the wider aspects of commissioning projects (such as finance)</b></p> <p>We discussed the role of the patient leader and considered boundaries with involvement. CB agreed that understanding and sticking to boundaries can be challenging. CB suggested to the group that it might be helpful to remind themselves that their role on the group is to <b>feel assured that the voice of the wider public has been heard and acted on</b>. Before asking a question at the group it can be helpful to think <i>'how does this question help me to feel assured that the project has engaged with the right people in the right ways and that the feedback is being used appropriately to develop the project'</i>. CB suggested that finance issues might be relevant if they impact on the way the project engages with the public or how the project acts on the feedback. CB encouraged patient leaders to avoid asking questions about wider financial issues in their patient leader role. He suggested that wider concerns about finance should be picked up separately and as an individual or campaign group.</p> <p><a href="#">Patient leader role</a></p> <p><b>3. How do we understand the needs and preferences of different cultures?</b></p> <p>There was general agreement that patient leaders and PPG members should have a good understanding of the needs and preferences of different communities (or at least an awareness that different communities have different needs). CB explained that the CCGs offer 'Equality and Diversity' training to patients but that these sessions were undersubscribed. It was suggested by the group that we develop shorter sessions which we can take out to PPGs and deliver locally. We also discussed online access to short courses.</p> <p><a href="#">Training calendar</a></p> <p><b>4. How can patient leaders get involved in the procurement process?</b></p> <p>One of the patient leaders shared her experience of being involved in a procurement exercise.</p>	
4.0	<p><b>AOB</b></p> <p>None</p>	
	<p><b>Date and time of next meeting</b></p> <p>The group will meet every 6 weeks. Following feedback from the group the meetings will be held alternately on afternoons and 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:  <b>Wednesday 10 August</b>  <b>Leeds Teaching Hospitals Trust, St James hospital</b></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?	We will evaluate the whole programme in the summer 2016 and ask for feedback on the website
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 policy has now been reviewed and patient leaders can claim expenses for printing in some circumstances.
Can you share details of involvement at the NHS trusts in Leeds?	Shared details of NHS trust membership schemes
Can patient leader learning lunches be run at the other CCGs?	Learning lunches have been offered to the other CCGs in Leeds
Can we have a guide for patient leaders?	This will be developed following a review of the programme in the summer 2016
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	In negotiation with the other CCGs re a citywide patient leader 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.	In the process of evaluating the patient leader programme. This will include a review of progress so far, recommendation based on feedback from patients and staff and an opportunity for people to comment on the

	recommendations.
CB to develop a draft volunteering policy and share with patient leaders	CB attending a volunteering conference in London on Mon 11 July. Will develop a volunteering approach following the conference.
CB to chase up progress on the SPA project and report back to patient leaders	