

## East Of England Patient Advisory Board Meeting

Chaired by - Lindsay Cook and Chrissy Marshall

Wednesday 21<sup>st</sup> November – Cambridge Professional Development Centre, Trumpington

MEETING OUTCOMES		
	<p><b>Attendees</b></p> <ol style="list-style-type: none"> <li>1. Lindsey Cook (<b>LC</b>) Co-chair</li> <li>2. Chrissy Marshall (<b>CM</b>) Co-chair</li> <li>3. John Reeve</li> <li>4. Eileen Rubery</li> <li>5. Glenn Edge</li> <li>6. Jean Goffin</li> <li>7. Sarah Mappedoram</li> <li>8. Phillip Wingfield</li> <li>9. Sam Brown</li> <li>10. Justine Thompson</li> <li>11. Neeta Masih</li> </ol>	
	<p><b>Apologies</b></p> <ol style="list-style-type: none"> <li>1. Paul Foulger</li> <li>2. Barbara O'Rourke (CRUK)</li> <li>3. Ray Anderson (<b>RA</b>)</li> <li>4. Marion Foreman</li> <li>5. Emma Frost (Macmillan Engagement lead)</li> <li>6. Debbie Adams (Teenage Cancer Trust)</li> <li>7. Ian Bradshaw</li> <li>8. Jonathan Rackham</li> <li>10. Susan St Maur</li> <li>11. Alan Stephens</li> </ol>	
2.	<p><b>Minutes of the Meeting – 30<sup>th</sup> August 2017</b></p> <p>Reviewed and approved.</p> <ol style="list-style-type: none"> <li>1. The CYP consultation is complete and a report is due in March 2018</li> <li>2. PAB ToRs accepted by the Board and to be reviewed every year</li> </ol>	LC CM
3.	<p><b>East of England Cancer Alliance November update – Sam Brown (SB)</b></p> <p>SB presented the latest update on the East of England Cancer Alliance, outlining its geography, challenges and the four key metrics - one of which is the 62-Day Cancer Waiting Times standard. There is a hold on national release of transformation funding until STPs are meeting the target of treating 85% of cancer patients within 62-days of referral. A number of STPs have improved their 62-Day CWT, in particular Norfolk &amp; Waveney, and have worked hard to achieve above the average 85% standard. As a result SB announced that transformation funding was</p>	

	<p>finally released on 17<sup>th</sup> November for two STPs: BLMK and Norfolk &amp; Waveney. The other four STPs will need to reach the 85% standard with evidence of sustainability over the next three months to be eligible for transformation funds.</p> <p>SB mentioned the following projects being worked on by the Alliance:</p> <ul style="list-style-type: none"> <li>- Recovery Package, a project to support patients living with and beyond cancer</li> <li>- Risk Stratified Pathways, supporting the best follow-up regime for patients including help to self-manage following treatment</li> <li>- Five Early Diagnosis projects: Lung, Prostate, FIT, Breast and Upper GI. Project briefs for these to be shared as ready</li> <li>- EoE Alliance is a pilot site for the National Quality of Life Metric. We have appointed Patient Leader Alan Bateman to lead on this, based at Ipswich Hospital Trust.</li> </ul> <p>SB also mentioned the Alliance Board membership has signed up to the East of England inter-trust transfer policy for transferring patients between services in a timely manner.</p> <p>SB will be working on mapping the various charities in the East of England and looking at how to engage all stakeholders. An important element of this work is to keep building on good relationships via the STP Programme Managers and Clinical Leads.</p> <p>Each STP will be reporting back to the Alliance Board on how they are supporting patient experience through all of their work streams, and particularly on how they will be involving patients. Network Cancer Groups were discussed. It was decided at the first meeting of the Clinical Advisory Board to keep these important groups, but funding and support has yet to be agreed. Patient voice and membership is key to their work.</p> <p><b>ACTION:</b></p> <ul style="list-style-type: none"> <li>- <b>Slides and Project Briefs to be circulated with minutes.</b></li> </ul>	
<p><b>4.</b></p>	<p><b>Group Work – feedback from STPs:</b></p> <p><b>Cambridgeshire &amp; Peterborough:</b> A Fit for the Future patient experience plan has been put together which shares reviews of the trusts in this STP. A final report will be ready for the 30<sup>th</sup> November. The report will draw together the actions for the trusts to build an overarching STP plan. It has been co-produced by the nurse leads and patient leaders. With the recent Hinchingsbrooke/Peterborough merger there is some work still to be done. The Programme Manager is having regular meetings with these Trusts.</p> <p><b>Norfolk &amp; Waveney</b> - Plans are being developed in time for next Alliance Board meeting on December 4. There is to be a new part-time role of Co-production lead at Queen Elizabeth Trust in King’s Lynn.</p> <p><b>Suffolk &amp; North East Essex</b> – Numbers taking part in the survey were relatively low. Plans being developed around actions and a timeline of responsibilities have been produced. Poor responses around receiving a care plan. Positive comments were received around the research question.</p> <p><b>Herts &amp; West Essex</b></p> <p>A little disappointed some clinicians and nurses had not heard about the NCPES. There is good work around the prostate pathway, particularly on 62 CWT. No evidence of an over-arching plan around NCPES as patients not yet involved in locality meetings. <b>RA</b> however has produced a report about his findings from the NCPES for West Herts Hospital Trust, which has been circulated to the STP Programme Manager and relevant CCG.</p>	

	<p><b>Mid /South Essex</b></p> <p>JR working together with SRO who sits on the locality board. Agreement to get a working group together: acute nurse, 1 Macmillan rep, CRUK rep and CCGs. Action plan for looking at responses, particularly where these are poor. Tumour site specific groups are coming up with plans. Attended a Primary Care GP summit where of 140 delegates only four had heard of the NCPES. Comms needs to be improved. STP Programme Manager is looking how patients are being involved in the Trust.</p> <p><b>BLMK</b> – no attendance due to ill health.</p>	
5.	<p><b>Radiotherapy Consultation – Paula Brown (PB)</b></p> <p>A review by NHSE will look at improving outcomes and sustainability of radiotherapy services across England. Aim for all to have access to modern equipment and treatment. Treatment for some cancers especially rare cancers may be undertaken at specialist centres. Each centre will be governed by a Radiotherapy Advisory Board/Network, for the EoE this will be via the Alliance. PAB members raised concerns for those who will be travelling long distances to centres. A PAB response will be collated by JT to form a part of the Alliance response and also as a stand-alone response to the consultation. Consultation closes on the 18<sup>th</sup> December.</p> <p><b>ACTION:</b></p> <ul style="list-style-type: none"> <li>- <b>PAB to send their comments on consultation to JT/Paula Brown by close of play 1<sup>st</sup> December</b></li> </ul> <p><b>Post meeting note:</b> Consultation deadline has been extended to <b>24<sup>th</sup> January 2018.</b></p>	<p>ALL</p> <p>ALL</p>
6.	<p><b>Feedback to the Cancer Strategy Interim Report – John Reeve (JR)</b></p> <p>JR presented on this the report and will re-circulate the link to the strategy. Progress has been made at national level but there is much to do and unclear how strategies are working 'on the ground'. There will be a meeting in January with National Cancer Directors Cally Palmer and Clinical Director Chris Harrison at which to present views. JR to circulate a survey on the Interim Report – responses would be much appreciated.</p> <p>JR was invited to a Primary Care GP event and presented "Tim's Story". Noted there was a lack of engagement around Holistic Needs Assessments. JR stressed the need to use patient groups as "ambassadors" to tell stories as they are powerful. The PAB will be doing more work on this. Anyone interested in telling their story to contact JT.</p> <p><b>ACTION:</b></p> <ul style="list-style-type: none"> <li>- <b>JR to circulate report and PAB to feedback on report by 22<sup>nd</sup> December 2017.</b></li> </ul>	
7.	<p><b>Cancer Alliance Website Review- Justine Thompson (JT) and Neeta Masih (NM)</b></p> <p>NM gave a short tour of the new Cancer Alliance Website, particularly focusing on the patient pages.</p> <p>JT asked PAB what they would like to see on the website and to send ideas to her. A few ideas were discussed in the meeting:</p> <ul style="list-style-type: none"> <li>- NCPES on the website</li> <li>- NM to send the generic email address to PAB</li> <li>- Landing page for the patients</li> <li>- PAB information leaflet including the Cancer Alliance logo</li> </ul>	

	<ul style="list-style-type: none"> <li>- A forum for patients on the website?</li> </ul> <p><b>Action –</b></p> <ul style="list-style-type: none"> <li>- <b>PAB information leaflet to be developed. Volunteers required for a working group (Please contact JT)</b></li> </ul>	
<b>8.</b>	<p><b>AOB and Future dates</b></p> <p>Thursday 15<sup>th</sup> Feb 10:30-15:00</p> <p>Tuesday 8<sup>th</sup> May 10:30 -15:00</p> <p>Wednesday 9<sup>th</sup> August 10:30-15:00</p>	