



Meeting of the Community Engagement Partnership

Monday 9th July 2018
5.00 – 7.00pm
The Key, Ipswich, IP4 2BB

PRESENT:

Vicky Thomson-Carr	Co-Chair	VTC
Claire Martin	Co-Chair	CM
Linda Hoggarth		LH
Irene MacDonald	IESCCG GB Lay Member for Patient & Public	IM
Gill Orves	IHUG	GO
Richard Squirrel		RS
Gill Jones	Healthwatch Suffolk	GJ
Susie Mills		SM
Caroline Webb		CW
Tina Rodwell		TR
Pat Durrant		PD
Jenny Pickering		JP
Ann Nunn		AN
Lynda Cooper		LC
Marian Carter		MC

IN ATTENDANCE:

Louise Hardwick	Head of Primary Care Partnerships	LH
John Troup	Acting Head of Comms, IESCCG & WSCCG	JT
Marielena Giner	Patient & Public Involvement Officer	MG
Christine Hodby	Designated Nurse for Safeguarding Adults	CH
Jacquie Knott	Manager of the Primary Care Liaison Nurses, NSFT	JK

APOLOGIES:

Maddie Baker-Woods	Chief Operating Officer, IESCCG	MBW
Jo Marshall	Voluntary Sector Representative	JM
Paul Gaffney		PG

MEMBERS OF THE PUBLIC:

Amber, David, Nigel

No	Item
1	Welcome and Declaration of conflicts of interest
	CM welcomed everyone to the meeting.
	Review of minutes for accuracy: <ul style="list-style-type: none">It was noted that RS was not present at the last meeting and should be moved from 'Present' to 'Apologies'.
	Declarations of conflicts of interest:

	<ul style="list-style-type: none"> • VTC declared that she has personal interest in the agenda items due to her daughter having Learning Disabilities. • CM declared that in relation to the action log item 'Pregablin' she works for an organisation that provides pharmaceuticals. • IM declared that she also works for a charity that supports children and young people.
2	Action Log – review and report on actions
	<p>ME : Staff member assigned to this action is not present to give an update.</p> <p>Employment support: JT is speaking to someone tomorrow who will be able to assist with this action.</p> <p>111 gender selection tab: Care UK have now been awarded the contract for 2018/19. It is suspected that there has been slow movement on this action due to the tendering process and that we should now be able to resolve fairly quickly.</p> <p>Wheelchair contract: It was advised that MG will be attending a meeting this week with the contracts team at Suffolk County Council to further ascertain the level of patient involvement they've had in the contract, and to ensure patient involvement is more comprehensive moving forward. A concern was raised; Why don't people know what's in the service specification? This information isn't a secret. MG advised that she will bring this up at the meeting.</p> <p>Rheumatology: No update as yet – members highlighted that this item has been on the action log for some time so we must obtain an update for the next meeting.</p> <p><i>Agreed Action: To chase this item and advise accordingly at the September meeting.</i></p> <p>Training funding panel: The person we need to speak to is on A/L, update to follow soon. IM mentioned that Richard Cracknell is bringing some proposals forward in relation to this, therefore we could ask him to attend a meeting in the future – group in agreement.</p> <p><i>Agreed Action: Invite Richard to a future CEP meeting.</i></p> <p>Wellbeing website – go live date confirmed as end of July. RS – update received from NSFT advising that bugs will be fixed and time line is 4 weeks (24th July). Website went live July 2016. Trust should be held to account, what is the CCG going to do to, 2 deaths have occurred recently. Irene – 2 meetings ago we mentioned a piece of work which is asking the providers how they do comms and engagement, we need to ask providers who is the designated person we put our concerns to? Action.</p>
3	Member Updates and Current Issues
	<ol style="list-style-type: none"> 1. CW attended the ranch meeting and will give the group feedback after the next one on 17th July. 2. GJ reported that Healthwatch have received approximately 5000 responses from the research they are currently conducting within schools.

3. RS has contacted Mersey Care who are part of the suicide alliance. They have reported that their view on suicide is that it's a 'preventable death' and said that even though somebody has a right to end their life, it is OUR right to prevent someone from causing harm to themselves. RS contributed that the CCG should be representing the same view and ensuring that this is a consistent approach not just across Suffolk but nationally. Anyone working in Mental Health services has a duty of care to prevent harm. It would be helpful to have a health professional's stance on this now in relation to the action log item.
4. TR advised that there is a member of the public here today whos daughter was recently refused entry to her school prom because she has a long term health condition. It's been reported that there are many other mums experiencing similar discrimination, whereby children are denied education because of health conditions. No one seems to inform the parents of their children's rights to an education up to the age of 25. Some mothers that are also ill themselves and even though in hospital, are still hounded by schools who seem not to understand or accommodate parents who are also chronically ill and the right of the child to have an education that fits their needs.
TR also commented that she too has experienced a problem with her son's school; no yearly review was conducted and her son has been educated by a tutor for the last 3 years. It seems that chronic illnesses are not listened to or taken seriously, and there is no protection for parents in these situations.
5. VTC gave her apologies for not attending the conference.
6. CM thanked the group and CCG staff members for their hard work in organising the patient conference, and provided some feedback; It was a really great event and we received positive comments from many attendee's.
7. LH reported that at a recent meeting it was raised that some surgeries prescribe paracetamol while others don't, and asked why there is no consistency?
LH advised that GPs are private businesses so unfortunately we can't obtain true consistency across the board. However, the CCG spend about a million pounds annually on prescribing paracetamol so all we can do is continue to campaign for people to buy paracetamol from pharmacies and supermarkets. VTC highlighted that if you ask for this product at a GP surgery they can't refuse to prescribe it, but they tend to refrain from offering it due to cost.
8. IM reported that the west Suffolk Lay Member has now joined the CCG Community Engagement Group. New members have also been appointed and we are currently considering holding an induction for new members.
9. SM advised that the Homeless Project now have an Outreach Worker in post. Ipswich have also been successful in getting £267,000 to spend on homeless issues which is great news.
10. GO gave some feedback on hospital blood tests – there is a specific time frame in which blood samples must reach the test labs and 50% of patients are currently having to have their bloods retaken as the hospital are missing this window. GO asked if this a service that the CCG commission?

Agreed Action – LH to look into this and confirm whether or not the CCG can help/advise with this issue

11. LC enquired about the delays she experienced with the Trusted Assessment project. JT advised that the team working on this project will be getting in touch with all volunteers involved to advise of the next step. The team wanted to engage and involve service users from the beginning of the project

	<p>which was perhaps a little too soon - they just need to recalibrate and will change their approach moving forward to ensure that volunteers are fully aware and happy with the involvement process.</p> <p>12. CM asked if CEP ID badges can be made for new members and LH.</p> <p>Agreed Action: MG to take photographs at the end of the meeting and ensure that these badges are made and provided at the next CEP in September.</p>
4	CCG Update
	<p>LH provided the CCG update, the key points of which included:</p> <ul style="list-style-type: none"> • The CCG had offered for Patient Participation Groups to apply for individual grants of up to £1000. GP Practice were approved for their application to purchase some scales in relation to weight management for children and young people. They were advised that they'll need to provide a wrap-around service and have appropriate support in place to help patients lose weight and monitor progress. Wickham Market Practice were approved for 'Train the Trainer' training in CPR. A group of 7 practices came together to employ a Link Worker that will be based within those 7 practices to give advice on varied Voluntary Care Sector issues. For example, if a patient goes to the GP about a family member being discharged from hospital and needs advice on their aftercare, they can now see the Link Worker, thus freeing up the GPs to attend to more patients. A question was raised about who will be training the Link Worker, LH advised that someone from the Voluntary Sector will perform this and CCG will train them as a Health Coach. • 70th Birthday celebrations: Various GP practices have been holding tea parties in celebration of the NHS' 70th year anniversary. These have been really humble and lovely to see people coming together in their communities. Stow Health did a 1940's tea dance and some practices used old equipment which provoked lots of discussion around the old NHS. Another surgery dressed up in 1940's outfits. There was an exhibition at Asda to celebrate the 70th NHS birthday on 5th July. At the next Governing body meeting the CCG have invited 70x 70 year olds to come along and have a tea party. Invitations are also open to CEP members. 24th July. 7 there will be young people present at the meeting who took part in a 'Sun Care' poster competition.
5.	Communications Update
	<p>JT gave an update on Communications, the key points of which included:</p> <ul style="list-style-type: none"> • As part of the Mental Health engagement work that is currently being undertaken, surveys have just been launched online. The CCH Mental Health team have received a good response so far via social media advertising. We'd be grateful if everyone could share the survey link within their networks. • 70th celebrations:

	<p>There have been several 'self-care' events to help with rural isolation. Lots of interest on the media. BBC Suffolk were at Ipswich Hospital last Tuesday to do a piece on the 'diabetes passport'. This passport enables those diagnosed to have some control over their condition.</p> <p>There was also media coverage on maternity at Ipswich Hospital and at a local surgery highlighting 'care navigation'. This was broadcast last Tuesday but we will send round the link to everyone.</p> <p>A question was raised - can we have the links/videos displayed on the website?</p> <p>Agreed Action: JT to send out links to CEP members and look into having these put on the website.</p>
6.	<p>Guest speaker on Learning Disabilities – Christine Hodby</p>
	<p>Christine Hodby, Designated Nurse for Safeguarding Adults at Ipswich and east CCG, gave a presentation on the programme for learning disability related premature deaths.</p> <p>This presentation is included within the attached documents.</p> <p>The following questions were raised by the group:</p> <ul style="list-style-type: none"> • Is suicide incorporated into these recorded deaths? CH: The cause of death doesn't affect this, it's for ANY death relating to a learning disability • Is heart screening available for people with a learning disability? Are the appropriate screening mechanisms in place to prevent premature deaths? CH: There is a lot of work going on to help people access the services they need. This programme will hopefully make a big difference and help us move forward, we will act locally on the information we obtain from the reviews. • A personal issue was raised – a member's daughter has not once been contacted by any service about her annual health check. One check per year is not sufficient for severe LD or health conditions. The daughter has spent the last year at deaths door due to bowel problems and sepsis, support and service from providers has to be constantly fought for on her behalf. In Suffolk we have lost our disability team, nurses are unable to manage their caseloads, crisis cases are going on and nothing appears to be done about it. Those with LD should have access to carers - our vulnerable people need to be looked after better. This shouldn't be a voluntary sector responsibility. Many people with LD are also on benefits which is a further barrier to them accessing the services they need. • What is the average age of death? CH: 30 years younger than the general population. This is usually below 50 years old. • How will people know to report a death and how to do this? CH: there is a comms strategy to look at this. • With regard to 'suspected' learning disabilities, isn't this going to prove problematic with the recruitment and workload of volunteers?

CH: Each case is quite a quick piece of work to complete – the investigation involves looking at a person’s childhood, their GP records and school/education where it is suspected we’ll find reported difficulties regarding learning and social interaction etc.

LD awareness training will be mandatory for all staff so that people can understand learning disabilities fully.

- How long does it take to complete a report – is there a timeline?

CH: It is expected to be complete within one week.

- A personal query was raised in relation to someone’s daughter who received a letter 4 months ago, detailing the cost of her care which was being taken out of her benefits. She receives £473 on a 4 week basis, and was asked to pay £382 of this allowance towards her care - with Suffolk Local Authority paying the remainder. The daughter has 6 hours per week of care to help her lead an independent life – in comparison to living in supported accommodation this cost is very small. Why should someone be expected to contribute such a large amount of money to their care when this is in fact saving the system a huge amount of money?

In addition, the parent has had to fight to allocate resources to the daughter and her physical health issues have been left with nobody getting involved. Her jaw has disintegrated due to an auto-immune disorder, and had to fight with the GP for a referral to rheumatology for investigation. People with a learning disability or mental health issue do not receive the level of healthcare they need and they are the most vulnerable.

- A good news story was mentioned by a member of the public and will be shared with Christine and the CCG following today’s meeting.

Agreed Action: MG to liaise with member and Christine to ensure this takes place.

- How does someone report a patient with suspected learning disability and will they be listened to, as often family members and GPs disagree on diagnosis and suspected conditions.

CH: Every death is taken seriously and the school reports will tell a lot about their learning difficulties and coping/social skills. There are lots of things we can look at that will tell us if this person had a learning disability. With regard to the doctor’s opinions, we look for letters and other such information on the GP record, not at what the doctors write about their patients.

- In relation to the coroners, how do we get people interested in these premature deaths? And what if there has been a conflict between the GP and family (for example drug issuing)?

CH: We speak to the family first and this information is extremely important to us. The conflicts will all be open for everyone to see and families will be prepared about any conflicts prior to seeing the report.

Agreed Actions: LH to talk to Christine about bowel passports, something seems to be missing as GPs are not linking in with this. Christine to send MG the presentation she shared today.

7. Guest speaker on Learning Disabilities – Jacquie Knott

Jacquie Knott gave an update on Learning Disability Nurses in Primary Care, the key points of which included:

- The programme was set up to improve the ability of Primary Care to respond to those with LD and related health conditions, to raise confidence about communication and reduce health inequality. Our focus is on making reasonable adjustments to cater for patient's needs.
- There are currently four Nurses spread across Suffolk in designated GP surgeries to support their service to people with a learning disability.
- We have priority on Annual Health Checks. People need to be listed as having a learning disability on the GP register to be invited for an AHC, we have found that many still aren't – there are missing people with known LD, or sometimes listing them as having a learning difficulty. Liaison Nurses are working with the surgeries to improve the registers
- Statistics for people in Suffolk are as follows;
2,711 people on the LD register for Suffolk East and West 2015-16, 3,191 in 2017-18. Of these 1,310 people had Annual Health Checks in 15-16 and 1,833 in 2017-18. The improvement has included knocking on people's doors to find out why people aren't attending their health checks.
The annual check is about surveillance – making sure they are on the radar.
- Half an hour with a GP, plus half an hour with a nurse is a Gold standard. Some GPs are not offering this standard so we are pushing this quality and assisting in order to achieve this – training is available to all surgeries and the CCG have invited expressions of interest in this training
- Both of the Suffolk People who died of constipation and featured in the serious case review lived in supported accommodation.
- The CCG and ACE have supported them to provide accessible formats for people with learning disabilities.
- We know that there are people in services who are not going to appointments, some of the work of the nurses is to contact these people and see why they don't attend and encourage them to do so.
- Many people need help in making choices about healthy eating so we need to improve awareness around this.
- Bowel management work is being done with staff in homes. The Liaison Nurse post covers 61 of the surgeries in Suffolk apart from 3 who have currently opted out. The liaison nurses in primary care are in contact with nurses in the hospital.

Questions and comments from the group and public included:

- Unfortunately GPs don't all understand the needs of those with LD. Jacquie said she also assumed a level of knowledge that isn't there. During the first year of this project they did work with GPs to educate them, now they do it at the GPs convenience and have a training pack that goes out to all. C The training includes consent, capacity, issues around learning.
- There are issues around the care in homes provided by social services – half an hour time slots are not enough time to see if the patient is actually ok and monitor/assess accordingly. Many carers are going in for only 10 minutes at

	<p>a time (possibly due to workload?) and this should be 30 minutes for each visit. Whether care is being funded or paid for by family or patient, cutting corners like this is unacceptable.</p> <ul style="list-style-type: none"> • Not every LD is clear cut, capacity to weigh this up and make the right decisions is not always there. Jacquie agree that capacity is not always recognised as it is complex - we need more awareness. • Regarding the carers who visit patients in their homes, it has been reported that many people see different carers each time so the carers are not able to get to know their patients properly which could result in missing something in their behaviour and how they present. Continuity is very important and it's been proven that this saves lives. • From a health professional/clinical point of view, we are conscious of the contradictions that are going on. Health checks for example – GPs should be achieving 100% statistically. The government has highlighted issues with people not paying for their care. We should see what others are doing, i.e. other Local Authorities who may have a process for recording time spent in homes - we must keep learning from external places and out of area. • A member of the public added that education for his daughter has stopped because of her fatigue syndrome - she should still receive tutoring. <p><i>Agreed Action: LH to take down contact details and look into this query.</i></p>
8.	Any other business
	None.
	Date of Next Meeting
	Monday 10 th September, 5.00pm – 7.00pm at The Key, Ipswich, IP4 2BB