**West Locality Meeting Minutes – Online on Zoom**

**Wednesday 20th October 2021**

**Introductions and apologies:**

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| **Attendees:** |
| Graham Goodwin | Carer, Carers Champion and Norfolk & Waveney Mind Board Member |
| Ali Ward | Carer and peer support representative |
| Alison Furniss | Family Voice, Carer |
| Steve Rourke | West Norfolk Carers and Lily Project |
| Sharon Brook | Chief Officer, Carers Voice |
| Sophie Little | Membership and Grants Officer, Carers Voice |
| Catherine Kennedy | Carers Voice and Co Production Facilitator |
| Pip Everett | Carers lead covering South and West, Norfolk & Suffolk Foundation Trust |
| Emma Harrison  | Patient Experience and Public Involvement Lead, Queen Elizabeth King’s Lynn NHS Foundation Trust  |
| John Newman | EEAST Community Engagement Group Member and First Responder for EEAST |
| David Russell | EEAST Community Engagement Group Volunteers for Norfolk  |
| **Apologies:** | Jan Crump, Jill Curtis, Caroline Holbrook |

Ali and Graham both agreed that the welcome pack to be sent to Carers, by Carers Matter Norfolk looks good. Graham asked whether information about the virtual cuppas will be included.

**Action:** Catherine to feed this back to the Carers Matter Norfolk Communications Team.

**Minutes, Decisions and Action Outcomes**

Uptake on previous training with Carers Matter Norfolk was low so other options are currently being looked at.

Alex Stapleton is now the Volunteer Coordinator at Carers Matter Norfolk and is working on the digital inclusions project, replacing Fiona Podolski.

**Action**: Share details of how to contact the volunteering/digital inclusions team. The email address to contact is cmnvolunteering@voluntarynorfolk.org.uk

Ali would like 5 more copies of the handbook.

**Action**: Carers Voice to arrange for 5 handbooks to be sent to Ali

Carers Voice now have 5 Carers Ambassadors in place who are working in their areas to raise awareness of the Carers Matter Norfolk service and Carers Voice.

Kerrie Campbell has now left Caring Together. Since the last West locality meeting Michelle Wilkins has joined Caring Together as Community Engagement Officer.

**What Matters to Me:**

A positive experience with Careline was shared. The person who came to install the alarm was very good at explaining how it worked and was very empathetic. Very impressed with the service.

Steve advised that Careline can also put in door sensors to alert Carers when the door is opened. Assistive technology may also have sensors available and bracelets. Another Carer shared their experiences with Assistive technology. The person they care for recently received a “Ring” doorbell which sends a message to a mobile saying that there has been activity at the front door. This was free of charge as it was through Assistive Technology.

A Carer shared their experiences with the lack of liaison between GPs and Chatterton House. Chatterton House need to do an assessment to provide a diagnosis before the GP can do anything and issue medication.

Issue with contacting GP surgeries discussed particularly with reference to Gayton Road surgery. People have been up to 40th in the queue and have been cut off. It is very hard to return calls to the GP if a call is missed or to call and ask a question.

Another experiences was shared about the ambulance service. A man who had fallen had to wait with their Carer for over 7 hours in an ambulance outside the Queen Elizabeth Hospital. There were approximately 15 other ambulances also waiting outside at the same time.

The ambulance service is keen to hear feedback from Carers.

**Action**: Carers Voice to send details to attendees after the meeting of how to provide feedback on ambulance services.

Kristen Hall has started as Communications and Engagement Lead – Programmes at the Norfolk and Waveney Clinical Commissioning Group.

**Action:** Carers Voice to feedback to CCG about problems with GP surgery.

Pip said that most surgeries work the same system. Similar experiences were shared about waiting times and being asked to call the next day as all available appointments have been taken. Some are trying to extend phone options so there is a separate button to press if you would like to ask a question. Similar experiences with dentists. There is a difference between surgeries but you have to be in relevant catchment area for surgeries.

Similar experiences with ambulances at the Norfolk and Norwich University Hospital. People are being told it would be quicker for a family member or friend to drive them to the hospital instead of waiting for an ambulance. Reliance put on Carers to get the person they are caring for to the hospital creates added responsibility and pressure. People may be going to A&E as they are not able to get an appointment with their GP. There should be an emphasis on promoting pharmacies.

**You Said We Did:**

* Emergency Plans: Feedback received from Carers that they would like an easier way to update their emergency plan form. Currently, you have to resubmit a new form. This has been raised with Norfolk County Council and they are working with their IT team to look for a solution.
* Hospital transport: Carers haven’t been allowed to travel with the person they care for in hospital transport, particularly to the Norwich and Norwich University Hospital (NNUH). Carers Voice has raised this with the Patient Experience Team at the NNUH and they are looking to work with ERS to raise awareness. This is still ongoing.
* Respite: Question raised about respite to James Bullion at Healthwatch AGM
* North Carers Meeting: Carers Voice have been supporting one of the Ambassadors to arrange a meeting with professionals working with Carers in North Norfolk to see how they can come together to support Carers.
* Carers have said that they want more contact with CCG: Carers Voice have arranged for Kristen Hall, Communications and Engagement Lead – Programmes, to attend a number of locality meetings
* Discharge to Assess: Carers Voice have been liaising with the discharge to assess teams and Carers have participated in meetings. Carers have been working with the Discharge Improvement Clinical Lead at the Norfolk and Norwich University Hospital to develop a next of kin/Carers/significant other card for discharge.

**Carer Involvement Opportunities:**

**East of England Ambulance Service**

The East of England Ambulance Service are keen to hear feedback from anyone who has used the service recently for themselves or the person they care for as part of their on-going patient and public involvement agendas, and their newly co-produced patient and public involvement strategy. They would really value the opportunity to hear your experiences, good and bad, and views on the East of England Ambulance Service. You can feedback by:

* Completing their survey- <https://www.eastamb.nhs.uk/contact-us/patient-surveys.htm>
* Sending comments to their PALS team <https://www.eastamb.nhs.uk/contact-us/pals.htm>
* **By phone:** 0800 028 3382 (freephone) or 01234 243320.
* **By email:** feedback@eastamb.nhs.uk
* **By post**East of England Ambulance Service NHS Trust (EEAST)
Patient Experience Team
Hammond Road
Bedford
MK41 0RG

They are also keen to hear experiences through a 1:1 feedback interview either face to face or virtually. The interview will be led by you with no set questions. It will allow them to hear your experience in a way that works best for you and to go onto greater depth then the patient surveys.

With the participants permission, they will record these interviews and be able to share them with their trust Board and staff so they can directly learn from Carers experience and improve patient care.

Please contact involvement@eastamb.nhs.uk if you would like to take part in an interview.

John has said that the feedback is very valuable to them. The Ambulance survey board is keen to get first-hand experience.

**Action:** Share details in the minutes and to everyone at the meeting via email afterwards.

**Carers Matter Welcome Pack:**

Carers Matter Norfolk have produced a welcome pack to be sent to Carers soon after they first contact the Carers Matter Norfolk service, so they have information available immediately while waiting to be contacted by Carers Matter.

Ali has asked if the handbook will be sent with this and whether there will be any physical copies available?

**Action**: Carers Voice to raise this with the Communications Team at Carers Matter Norfolk

**Sandringham Christmas Market Trip:**

Caring together are arranging a trip to the Sandringham Christmas Market primarily aimed for Bereaved Carers. This is taking place on Friday 19th November. They are looking at a bus from Norwich to Sandringham with a few stops on the way. There is public transport that goes from King’s Lynn to Sandringham every hour.

**Action**: Catherine to check with Caring Together about best person to contact regarding the trip as all carers are welcome to join, and to share with group after the meeting.

**Queen Elizabeth Hospital Kings Lynn, written update from Emma Harrison**

They have received 200 Unpaid Carers Wellbeing Packs from Norfolk County Council. These have been distributed as follows: 20 to Cancer Services,12 to the King’s Lynn branch of Norfolk and Waveney Mind and 50 will be going to their staff who are unpaid Carers. The remaining packs will be distributed to - Patient Advice and Liaison Service (PALS), Discharge Lounge, Discharge Liaison Team (– who organise patient discharges from the hospital – this will hopefully encourage them to ask a question about Carers), Family Liaison Officers – they meet with all patients on the wards and will be able to find out if patients have a family carer or someone who looks after them at home, Relatives of patients at end of life, Chaplaincy – via the their faith room, Dementia Team, Women andChildren’s team to promote young Carers and Parent Carers.

Emma would like to know if Carers have any other suggestions of where the packs should be distributed. Alison Furniss said that Family Voice could share them at stands and events.

**Action:** Carers Voice to share Emma Harrison’s contact details with meeting attendees after the meeting, via email. They are also further down in these minutes.

Pip explained that NSFT have not had a massive uptake on packs as Carers are not coming into buildings. They have attached a date sticker to the pack to advise Carers to check the expiry dates of some of the items within the pack. Generally, the packs have been very well received.

Emma Harrison recently attended the Norfolk Young Carers Forum and also updated that the Hospital are currently working on their Carer Friendly tick application. They would be grateful if any Carers would like to look at the application.

Alison is pulling together the Carers Policy which is based on the policies from the other acute Trusts in Norfolk and Waveney. They would appreciate if members of Carers Voice would be interested in reviewing the policy so they can ensure they have captured everything that is important to Carers.

They have worked up a training plan with local carers organisations to roll out to staff. They will share more information about this as they proceed with the roll out.

They continue to add to their website and are looking to introduce an intranet page for their staff. This would either support staff as unpaid Carers or be a reference point for professional questions. They would welcome input from Carers Voice to add to their website. They are going to contact Norfolk and Waveney Mind for their input following a suggestion from Carers Voice.

They will be raising awareness on Carer’s Rights Day in the hospital to library to staff. It will be staff only due to visiting restrictions and the library only being available to staff. They will have leaflets from local Carers organisations, will display the wonderful Carers pack, have details of their champions, and how to sign on to training sessions and celebrate virtually what is happening in other hospitals and organisations that are supporting Carers.

 **East of England Ambulance Service, John Newman and David Russell**

The ambulance service is rushed off its feet. CCG are working on a simple leaflet updated people.

They would really like input from Carers in their Community Engagement Group. There is a leaflet attached to the minutes about this.

The East of England Ambulance Service covers 6 counties of East Anglia. Between April 2020 and March 2021, they had over 1.2 million calls. They have nearly 400 ambulances and have an average of 4000 calls per day.

Preventing the need to call an ambulance includes annual health checks, Covid vaccinations and boosters, annual flu jab and shingles vaccination. It is important to take medication as prescribed, keep a constant temperature and have regular meals and plenty of fluids. Good lighting is important especially on steps and landings. Try and reduce risks where you can.

Some of the things you can do to prepare in case you need to call an ambulance include having a large and clear door number, keep path clear, a key safe and number, guidance/someone outside, previous medical history and list of medication.

A Lions club “message in a bottle” can be used to store important information about your health in the fridge. It is a small plastic tub but any plastic container can be marked up and used. Emma Harrison has a number of these at the hospital. Graham and Ali to arrange to collect a message in the bottle from the Queen Elizabeth Hospital King’s Lynn.

You can get help from pharmacists, walk in centres, GPs, urgent care centres, 111 (non-life-threatening emergencies) and 999 (life threatening emergencies).

A question was raised about the 3 words app. The service is currently looking at questions of consistency but there are plans to discuss use in the future.

**Action:** Carers Voice to share handout information from the East of England Ambulance Service with the minutes.

**All Age Carers Strategy**

The previous Carers strategy in Norfolk was from 2014-17. This is the first time there has been an All-Age Strategy that covers Norfolk and Waveney. Carers Voice is leading the consultation of the strategy to find out what Carers need and want to support them in their caring role.

Carers Voice has been working with Carers and Carers groups including West Norfolk Carers, Young Carers and families, Parent Carers, Young Adult Carers, Carers Ambassadors and Healthwatch to co-produce the survey which is the initial consultation document. It has been interesting to incorporate everyone’s ideas as these have varied between group of Carers and to balance the number of questions. The official launch of the survey will take place shortly with focus groups to follow which will pick up additional areas. The initial findings will be presented to the Health and Wellbeing Board in December.

Carers felt ensuring their Cared for is getting the treatment they need is of great concern to Carers. There needs to be a joined-up approach in health services. Contacting GP’s at the moment is very difficult and causes stress. Experiences of services not liaising with each other in particular Chatterton House and GP’s.

Concerns about crisis within mental health service were discussed and to look at how this could be addressed

Carers being relied on was highlighted with an example of a Carer whose husband is in hospital. The Carers can’t leave the house or use public transport and both care for their adult child. Their cared for has their own flat but they have been living with their parents, and since their parents are caring for them, services are not willing to help. Assumption that Carers will do it and take the burden. There is a feeling that services don’t have to worry about them as they have someone else looking after them.

A lack of continuity with Social Workers was discussed, with social workers turning up to 2 or 3 appointments before closing the case and not offering support on an ongoing basis. Sharon emphasised that social workers are often working hard in the background and have limitations in the support they can offer.

Sharon explained that Carers Voice are exploring a focus group regarding mental health for Carers to share experiences and to inform the findings of the strategy.

Another issue was shared about a Carer who was asked to attend an appointment with the person they care for at Chatterton House. However, when they got there, they were not allowed to go in although they had specifically been asked to be with the person they care for during their assessment.

Concerns about future services were discussed including GP surgery waiting times and being able to see a doctor face to face. Waiting times on the phone cause a lot of anxiety. An example was given when a Carer was relieved they had a physiotherapy appointment at the surgery so they could physically speak to someone there.

Steve asked whether Chatterton could be asked whether Carers are able to attend meetings?

**ACTION:** Pass feedback about health services to Kristen Hall.

Graham has asked about paper copies of the survey for his group members. Graham said the best way to get the survey to his members is through him.

Emma explained that they have a letterbox in the hospital but this is currently in her office until it is 'activated' by Healthwatch.

Graham and Ali are happy to complete a test version of the Strategy survey.

Carers suggested a focus groups to concentrate on issues around neurological and mental health.

**Professional Issues:**

**Emma Harrison, Queen Elizabeth King’s Lynn NHS Foundation Trust**

Emma Harrison explained they have a story from patients and Carers at their Trust Board every month who share information about their whole experience with the hospital. Patients and Carers receive support and a brief prior to the board.

People can contact Emma directly if they are interested.

Emma.Harrison@qehkl.nhs.uk

Tel: 01553 613613 x 2432

Working Days – Mon- Fri - 8am – 3pm

**James Stewart, Norfolk County Council**

Carers Emergency Planning:  The form which Carers helped co-produce is now live; although there are some issues Carers raised regarding functionality and the form not allowing Carers to log back in and update information. James has met with the relevant team to see if they can build something into their system to enable Carers to report changes to their plans in the future. It’s very early days and unlikely to take place until later this year; however, it looks likely they can do something.

For the time being Carers will need to follow the same process of completing the form from scratch, to report changes; but hopefully Norfolk County Council can achieve a resolution to this. James wanted to ensure Carers are kept updated to show that they are listened to and that Norfolk County Council take such matters seriously and are working to find a solution.

Also, if you have any other comments/ amendments you feel are needed for the form, please email info@carersvoice.org and we will ensure these are passed to James.

Safeguarding: Following on from meetings with Carers that were supported by Cares Voice, they are looking at launching a campaign in early 2022 to reach out to Carers and those supporting them from a range of agencies/ organisations. This will educate on the different types of abuse, support available and how to access it. Carers will be inputting their views on the content to be delivered including pitch, tone and materials.

Replacement care: This continues to be an area which Norfolk County Council recognises can be frustrating for Carers in terms of not being able to advance book replacement care. They are in the process of recruiting a commissioning manager to tackle this area and when they are in a position to take this forward, would welcome the chance to have a focus group of Carers, to help with shaping this support offer.

Website update: They are currently working on reviewing current web content, with a view to making it more accessible and informative for Carers. When this starts to take shape, James would like to share it with Carers to find out the key information they feel would benefit them most in respect of information and advice.

**Future Agenda Items:**

All Age Carers Strategy

**AOB:**

Graham to pick up 5 wellbeing packs and a few Lions - “message in a bottle” from the Queen Elizabeth hospital

**Next meeting: Date to be confirmed**