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

**Monday 3rd November 2021**

**Introductions and apologies:**

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| **Attendees:** |
| Dorothy Wood | Carer |
| Juliet Nusser | Carer |
| Christina Watkinson | Carer |
| Jay Page | Carers Ambassador, Carers Voice, National Federation of Women’s Institutes  |
| Deborah Martins | Carer |
| Joyce Bell | Carer |
| Malcolm Court  | Carer, Member of Carers Voice |
| Mary Ledgard | Ex Carer, Carers Ambassador with Carers Voice |
| Christine Little | Governance and Quality Lead, Norfolk Community Health and Care NHS Trust |
| Catherine Kennedy | Carers Voice Co Production and Facilitator |
| Sophie Little | Membership and Grants Officer, Carers Voice |
| Denys Ngu | Community Development Worker, Norfolk County Council  |
| Pip Everett | Carers Lead, Norfolk and Suffolk Foundation Trust  |
| Kristen Hall | Communications and Engagement Lead- Programmes, Norfolk Clinical Commissioning Group |
| Alys Duberley  | Service Manager for Community Team, Carers Matter Norfolk |
| David Russell | EEAST Community Engagement Group Member and First Responder for EEAST |
| John Newman | EEAST Community Engagement Group Volunteers for Norfolk |
| **Apologies:** | Sharon Brooks, Paul Corder, Emma DeSouza, Kate Spain |

**What Matters to Me, Community Hubs and feedback for the Clinical Commissioning Group**

Hospitals and GP’s need to do more to accommodate people with autism and learning disabilities in Norfolk. Dorothy attended a meeting describing the work they are doing in Bedfordshire. At the James Paget Hospital, Rebecca Crosley set up a Covid-19 vaccine clinic for people with learning disabilities and autism which was really successful. This did not exist at the Norfolk and Norwich University hospital. The James Paget Hospital also had offered open days for people to look round, familiarise themselves with the environment and ask questions. Kristen explained that the CCG have been discussing Rebecca’s success and are looking at building on this. All appointments across health services should have adjustments for people with learning disabilities and autism. Tesco has a quite shopping hour. Could be an idea for GPs to have a similar thing.

Some Carers and the person they are caring for, have been offered their vaccination at home. This was offered through their GP. Alys has said that this has been consistent across all GP’s for people with serious mobility difficulties. However, this is less consistent for people **who have sensory needs**.

A Carer shared their experience of accompanying the person they care for to their Covid vaccination. They were made to feel uncomfortable for being there with them and felt that they were only able to attend by insisting. People need to be aware that vulnerable people need support, and a bad experience could put them off in the future. In the end, the GP thanked the Carer for accompanying the person they care for.

Another Carer shared their experience with the Norfolk and Norwich University Hospital (NNUH) a few years ago. They contacted the hospital to explain that they would need to accompany the person they care for. When they arrived, they were told that they were not allowed in. However, they received a call shortly afterwards, saying their support would be helpful. The NNUH Carers Forum are trying to raise awareness that Carers can enhance a person’s stay in the hospital.

The NNUH has a Carers passport. A lot of Carers do not know about this. Kristen explained that work is currently taking place with the Carers passport and how this is utilised by Carers.

Carers are crucial to making sure the person they are caring for is able to communicate while in hospital. A Carer shared an experience of accompanying the person they care for into hospital. They were not given time to ask questions so had they not been there, the person they care would have said yes to everything asked.

Questions were asked about the NHS computerised system. There should be a note saying that the patient has a Carer/essential companion. To register as a Carer at your GP surgery, the person you care for needs sign to give permission for you to attend with them. Experiences are very varied across departments. The NNUH are working to improve Carer Awareness with staff.

Kristen asked the group about receiving the flu vaccine and Covid booster. One Carer explained that they and the person they care for had not been sent any information about it despite them being classed as vulnerable. Kristen explained, that if you are eligible, you do not need to be contacted to book the flu vaccine. However, you do need to be contacted regarding the Covid booster as this needs to be 6 months after your second vaccine.

Another Carer’s friend had booked to receive the flu vaccine online at Castle Mall but when they arrived, there was no record of their booking so they were unable. Eventually, they got the flu vaccine from a local pharmacy. Without assistance, it would have been too complicated to book an appointment online and an obvious phone number to call was felt a better idea.

Kristen explained that you can use the NHS website to search your postcode to find a pharmacy near you that offers the flu vaccine. <https://www.nhs.uk/service-search/pharmacy/find-a-pharmacy-nhs-flu-vaccine-service>

A Carer asked how long to expect to wait for a district nurse to administer the vaccine? The person they care for is due for their Covid booster in a few weeks and they wondered if they would get the flu vaccine simultaneously. Jay advised calling to double check if they will receive both vaccines at the same time

**Action:** Kristen to take feedback from the meeting forward.

**Minutes, Decisions and Action Outcomes:**

One Carer spoke about a Carer experiencing problems with discharge. Dates keep changing and they do not know when the person they care for is coming home or what measures need to be put in place for their return. They have had to make a lot of phone calls to get any information and find out what is going. Very disconcerting that dates keep being changed. Mary explained that it is a government edict that assessments and care plans are completed once someone is back home. Research says that the best place for people to recover is at home.

Pip expanded on the lack of communication around discharge Carers have been experiencing. One Carer received a call to discuss discharge when the person they care for had already been home for a week. There seems to be a lack of communication within the team. Someone makes a phone call saying that the person you are caring for is coming home then you do not hear anything else. It causes Carers anxiety as you do not know what needs to be in place e.g., a bed downstairs. One person was transferred between multiple hospitals and it was very difficult for the Carer to get any information. They additionally had a short stay in a care home and it ended up being noted as their permanent address instead of their home address. Communication is very important, especially with ensuring equipment is in place before anyone is discharged home.

**Action:** Catherine to raise this with James Stewart and the Discharge to Assess Team

Christine explained that from a community perspective, the integrated care system is working on a proforma for discharge. Christine asked whether it would be helpful to bring a Community Matron along to a future meeting to highlight a community perspective on discharge.

**Action**: Catherine to liaise with Christine about a future meeting

It is a big responsibility to take charge of monitoring medication. Carers are not always given clear guidance on medication they are responsible for giving or how to dress a wound. Carers need a chat with a professional before discharge and an opportunity to ask any questions and be reassured.

**Action:** Catherine to share this feedback with James Stewart as he is looking at the training offered to Carers by Norfolk County Council.

In one circumstance 2 people were required to assist a card for with mobility. Two care workers were arranged to come in at certain times but the Carer was left for the rest of the time to care for them on their own. Hospital training for mobility need to exist in such circumstances.

The majority of each day, the responsibility for care falls to just the Carer and this is felt not to be recognised by the discharge to assess process.

Because the discharge to assess system has been introduced without much publicity it was felt it is not known widely. It might come as a shock to people if they have been in hospital before, as it is a different process. Mary has raised this at a recent meeting regarding discharge to assess. At the meeting, there was a whole presentation and Carers were mentioned only once which is very worrying.

Norfolk Swift Response is a free 24-hour service you can call if you have an urgent, unplanned need at home but don’t need the emergency services. More information can be found at <https://www.norfolk.gov.uk/care-support-and-health/start-with-social-care/urgent-help/get-urgent-help-at-home-norfolk-swift-response-team>

Juliet asked if anyone had had any respite over the last year. Dorothy explained that there is never anywhere suitable for her circumstances. One Carer felt if you keep your head down, services assume everything is OK. So, unless you ask for help, you do not get it.

Nicky Smith from NCH&C has been liaising with Kerrie Campbell from Carers Matter Norfolk in the past. They are working to increase Carer Awareness and training to help support staff with fundamental awareness of Carers.

Carers spoke of the possible differences between the public and private versions of the person you are caring for which can lead to an inaccurate picture when an assessment is being conducted. Therefore, it is important to have Carers input. Overnight respite care is very difficult to get.

**Action:** Catherine to raise this with James Stewart, Kristen Hall and the Discharge to Assess Team

Alex Stapleton is now the Volunteer Coordinator at Carers Matter Norfolk and is working on the digital inclusions project. Carers can contact Carers Voice if they know of any Carers that would benefit from a tablet loan.

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

Uptake on previous training with Carers Matter Norfolk was low so other options are currently being looked at. Feedback that he way it was presented previously caused difficulties. A list of available options was offered on a number of dates but only if there was enough interest in the session did it go ahead. Carers could not really add a date to the diary.

Joyce shared information about the Norfolk and Norwich Hospital University Carers survey.

**Action:** Share link to the survey with the minutes. <https://ratemynhs.co.uk/survey/7f09eb21-0de2-40f7-9540-a86344431098>

**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 ongoing 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 and views. 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. They are keen to hear about all experiences, good or bad. 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 into greater depth than the patient surveys. With the participants permission they record these interviews, to enable them to share them with their trust Board, and staff to directly learn from your experience and improve patient care.

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

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

Demands on the ambulance service are growing. 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.

Prevention 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 have any influence.

Some of the things you can do to prepare in case you need to call an ambulance include: large and clear door number, keep pathways clear, have *keysafe* and number, guidance/someone outside, previous medical history and list of medication.

A “message in a bottle” can be used to store important information about your health in the fridge. David has a number of these available.

**Action:** David to send the bottles to Carers Voice so they can distribute to Carers that have requested one.

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

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

Ambulance service prioritisation of strokes was queried. If people are not breathing or are catastrophically bleeding, they will take priority – category 1. But John wanted to reassure the meeting that category 2 calls are very high priority also.

If a transient ischaemic attack (TIA) can be recognised and dealt with, preventative measures for a stroke can be put in. John advised not to hesitate to call the ambulance service if you notice any signs or symptoms. The FAST test can be used to recognise signs of a stroke. This involves looking at a person’s face, seeing if they can raise their arms and listening to their speech. Tell control this when making a 999 call. Observations from family and friends are crucial and can help raise the alarm.

More information can be found at <https://www.nhs.uk/conditions/stroke/symptoms/>

Some Carers have been advised to take the person they care for straight to A&E as this would be faster than waiting for an ambulance. Similar experiences outside of Norfolk.

A question was asked about Careline and the costs. There is an annual charge and monthly fee of around £15. Contact your local council or Norfolk County Council. Assistive technology can also help with the use of Alexa’s and Ring brand doorbells.

**Action**: Share link to assistive technology. <https://www.norfolk.gov.uk/care-support-and-health/support-for-living-independently/making-living-at-home-easier/assistive-technology>

David and John explained about the Community Engagement group and asked if anyone would like to receive any further information about this.

**Action:** Catherine to send information to Jay

**You said, we did**

* *Emergency Plans*. Feedback received from Carers that they would like an easier way to update the Norfolk County Council online 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 (ERS), 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/Replacement Care*. Question raised about respite to James Bullion at Healthwatch AGM who explained the shortage.
* *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 the CCG. Carers Voice have linked in with Kristen Hall, Communications and Engagement Lead – Programmes, to attend a number of locality meetings
* Carers Voice have been working with Carers Matter Norfolk to see how Carers can be involved in the recruitment of new staff.
* *Welcome Pack:* Carers Matter Norfolk have used the feedback received from Carers to produce a welcome pack that will be given to Carers who are referred to the service.
* *Discharge to Assess*. Carers have been liaising with the discharge to assess teams. 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:**

**Short term bed offer team, Norfolk County Council**

Short term beds are for when someone in hospital no longer needs hospital care but cannot be discharged without longer term plans being put in place. They transfer to a care home usually for a 6-week period while a long-term care package is put in place. Norfolk County Council are looking for feedback and would like to ask Carers 3 simple questions about their experience.

**All Age Carers Strategy for Norfolk & Waveney 2022-2025**

The last Carers strategy was from 2014-17. This is the first time there has been an All-Age Carers Strategy that covers Norfolk and Waveney. Carers Voice will lead the first part of the strategy to find out what Carers want and need from health and social care to support their needs in the future.

Carers Voice have been working with Carers groups to co-produce the strategy including West Norfolk Carers, Young Carers and families, Parent Carers, Young Adult Carers, Carers Ambassadors and Healthwatch. It has been interesting to incorporate everyone’s ideas as these have varied between group of Carers. The survey will be launching next week with focus groups to follow.

**Professional Issues:**

**Carers Rights Day, Thursday 25th November 2021**

Carers Voice are planning another online event including fun activities and information. We will be sending out Zoom link nearer the time but it will take place on 24th November from 10.30am.

**Pip Everett, Norfolk and Suffolk Foundation Trust (NSFT)**

NSFT are relaunching the Triangle of Care during the week of Carers Rights Day. On 26th November there will be an event open to everyone on the 26th November with speakers on Carers Rights and Carers stories.

More information on the Triangle of Care can be found at <https://www.nsft.nhs.uk/triangle-of-care>

**Action**: Carers Voice to share the poster for the NSFT Carers Rights day event with the minutes.

**Christine Little, Norfolk Community Health and Care NHS Trust**

They are working on Carer awareness and supporting teams. It is hugely important for community staff.

**Denys Ngu, Norfolk County Council**

Denys is facilitating an online peer support group for people with arthritis. They meet on the second Wednesday of each month from 1-2pm. More information can be found at <https://www.lumi.org.uk/activities/view/online-arthritis-support-group/>

**Action:** Denys to email Carers Voice poster to share on social media.

Joyce said the Community Sport Foundation have sessions for people over the age of 55 to stay active. <https://twitter.com/CarersVoiceNW/status/1453642706018869251/photo/1>

**Action:** Carers Voice to research the Community Sport Foundation and share information on social media.

Covid has made people more isolated as they do not feel safe meeting with groups. Carers Matter Norfolk hold virtual cuppa sessions for Carers across Norfolk to come together and share experiences.

**Action**: Carers Voice to share details of the cuppa with Joyce

James Stewart Norfolk County Council Operational lead – Adult Carers has provided the following feed back:

*Carers Emergency Planning:*  The form which Carers helped co produce is now live. There are some issues Carers raised regarding functionality and the form not allowing Carers to log back in and update information. Their IT team are confident t they can build something into their system to enable Carers to report changes to their plans. it is positive news but unlikely to take place until later this year.

For now, Carers need to follow the same process of completing the form from scratch, to report changes; until Norfolk County Council can achieve a resolution to this. James wanted to ensure you are kept updated to show that they are listening and 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, supported by Cares Voice, they are looking at launching a campaign in early 2022. This is to reach out to Carers and those supporting them from a range of agencies/ organisations, to educate on the different types of abuse, support available and how to access it.  It has been arranged for Carers who have previously supported in this area, to have their input and views on the content of this.

*Replacement care*: This continues to be an area which Norfolk County Council recognise 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. They would welcome the opportunity to have a focus group of Carers, to help with shaping this.

*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, it would be great to share with Carers to find out they key information they feel would benefit them the most in respect of information and advice.

It was asked whether respite is available at the moment. Catherine explained that as far as she knew some respite is still happening, depending on circumstances.

James is also looking at the training offered to Carers by Norfolk County Council.

**AOB:**

“Alexas” can be really helpful but it is important to keep an index of the terminology used. A Carer described a situation in which the Alexa didn’t understand what they were saying. Others shared experiences of Alexa being useful. It can be used to turn lights on and off as well as asking the date and time.

Mary asked if she could be sent the details of how to feedback to the East of England Ambulance Service

**Action:** Carers Voice to email Mary details.

Malcolm shared details about the group in Norwich for Carers who care for someone with mental health needs. The group is back to meeting face to face and meets at the Quakers Centre Norwich on the second Tuesday of each month.

Joyce is going to ask about discharge to assess at the Norwich and Norfolk Hospital Carers Forum which is taking place on 4th November.

**Next meeting: Wednesday 16th February 2022 at 10.30am**