PATIENTS' FORUM

FOR THE LONDON AMBULANCE SERVICE

Improving the Diagnosis of Stroke in Emergency Medicine
Dr Nick Mann, Hackney GP
& Karen Kennedy

Report on Patients' Forum Public Meeting
Monday, MARCH 25, 2024

A person loses 2 million nerve cells for every minute they don't receive medical treatment during a Stroke, so getting to hospital early really is a lifesaver.

PATIENTS' FORUM FOR THE LONDON AMBULANCE SERVICE

The Patients' Forum has monitored the LAS and other urgent and emergency care services across London for 20 years. Its members are patients and local people who examine services both as users and active lay people. It obtains the information it needs to monitor health services from many sources including, service users, the LAS, the Commissioners and NHS service providers across London.

The Forum raises awareness of the needs and views of patients and the public and attempts to place them at the centre of health service decision-making.

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VERY SPECIAL THANKS TO:

- **DR NICK MANN**
- **KAREN KENNEDY**
- **DR FENELLA WRIGLEY – LAS Chief Medical Officer**
- **MICHAEL WARD – Deputy Director of Clinical Safety and Compliance**
- **ALAN ALEXANDER for managing the meeting.**
- **MALCOLM ALEXANDER for Chairing and organising the meeting.**

Permission was given by those who attended to record the whole meeting.

ABOUT DR NICK MANN & KAREN KENNEDY

Dr. NICK MANN HAS WORK AS A GP IN HACKNEY FOR 37 YEARS.

HE IS AN EXPERT IN PRIMARY CARE AND HAS ALSO WORKED IN THE LAS, EMERGENCY OPERATIONS CENTRE DURING THE AMBULANCE STAFF STRIKE IN 2023.

NICK'S WIFE KAREN KENNEDY PHONED 999 TO GET EMERGENCY CARE FOR NICK WHEN HE HAD A STROKE.

SHE WAS DEVASTATED WHEN THE LAS REFUSED TO PROVIDE IMMEDIATE EMERGENCY CARE

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SUMMARY OF FINDINGS FROM THE PATIENTS' FORUM MEETING

● Dr Nick Mann's Stroke symptoms were not picked up by LAS 999 using the MPDS algorithm (USA owned software). MPDS does not include: "sudden inability to read", as a stroke symptom.

● It was agreed by participants in the Patients' Forum meeting that "sudden inability to read" is a 999-symptom and should prompt immediate suspicion and recognition of a stroke diagnosis.

● The 999 call-handler did not seek further advice from available Paramedics and Nurses within the Clinical Hub (Emergency Operations Centre).

● An LAS video assessment would have assisted diagnosis, but would have required a Paramedic to attend the patient on-scene.

● It was confirmed by the Senior Lead for the Clinical Hub (EOC), Mike Ward, that "sudden inability to read" is recognised by the LAS 111 NHS-Pathways algorithm as a symptom of stroke, but not by 999 MPDS.

LAS Response: Alexia is NOT recognised by NHSP, but acute visual disturbance is (Alexia is a*cquired* deficit in ability to interpret written language).

● Dr Fenella Wrigley stated that information from the International Academies of Emergency Dispatch website is that the FAST algorithm is more effective than on-scene ambulance crews at detecting strokes. It is accepted that this stands in contradiction to 2014 research.
https://pubmed.ncbi.nlm.nih.gov/24576912/

LAS Response: This is information from the International Academies of Emergency Dispatch website relayed by Dr Wrigley. It is acknowledged that there is alternative evidence from research published in 2014.

● The 2014 research suggests that dependence on the FAST algorithm is poorly predictive of stroke diagnosis overall, and substantial numbers of strokes are consequently missed through use of the FAST algorithm.

● Use of the BE-FAST algorithm reduced strokes missed by FAST from 14% to 4.4%. BE-FAST is not currently used by the LAS.
https://pubmed.ncbi.nlm.nih.gov/28082668/

- Courtney Grant highlighted evidence that use of algorithms can lead to an 'over-dependence' and that Clinicians and Call Handlers may become over-reliant on such algorithms, causing important symptoms and diagnoses to be missed.

LAS response: The algorithms being referred to here (MPDS) are being utilised by non-clinicians. They are an assistive tool for non-clinicians who use them to support their assessment and experience to determine the most appropriate response for the patient.

- Multiple organisations must collaborate and agree to any alterations or updating of algorithms. It's not clear whether these remote organisations operate within a clear, effective and efficient chain of command and communication system, to quickly enable necessary changes to occur.

FURTHER DATA REQUIRED:

- How many Strokes and other serious diagnoses are predicted to have been missed in London and nationally, as a result of the use of algorithms.

- Is rate of missed diagnosis increasing over time, and would we know if it was?

- Ten different ambulance services operate in England and may use algorithms which vary in the ways they respond to clinical input. How is national performance coherently evaluated?

- How are changes to algorithms by NHS-Pathways and MPDS recorded and reported to ambulance services?

- When will MPDS be updated nationally to reflect "sudden inability to read" as a stroke symptom?

INITIAL CONTACT BETWEEN DR WRIGLEY AND DR MANN

Contact was made directly to Dr Wrigley by Malcolm Alexander on 28th December 2023. This was an email to Dr Wrigley who responded back to Malcolm Alexander directly expressing her sadness about Dr Mann's experience, offering to contact him herself. She provided some reassurance that patients with chest pain or strokes remain a high priority for LAS and that this is reflected in the new LAS Strategy. Dr Wrigley made direct contact with Dr Mann and held a meeting with him and his partner Karen Kennedy on 18th January 2024.

Dr Nick Mann and Karen Kennedy Presentation to the Forum Meeting

Dr Nick Mann who has been a GP for over 30 years, suffered two major heart attacks and was treated at the Bart's Coronary Unit. On the day following discharge from the Coronary Unit he suffered a Stroke.

His wife Karen Kennedy called 999 and described Nick's symptoms, but the 'call-handler' said that his symptoms – sudden loss of ability to read text - according to the FAST test and algorithm, failed to meet the diagnostic threshold for Stroke. Karen said that Nick as an experienced GP was sure he had suffered a Stroke, but the call-handler refused to send an ambulance and advised Karen to call 111 for a more detailed review of his symptoms, and the possibility of an ambulance being provided through that alternative route. Instead, they decided to call a taxi which got them to Homerton A&E at speed. An ambulance then took Nick to the Royal London Hospital (RLH) Specialist Stroke Centre, where he waited approximately 16 hrs in A+E for a bed. He has since made a good recovery.

Karen described her shock at this awful experience when Nick was in a very vulnerable state of health and an emergency response was refused by the LAS. Nick said that from his clinical experience, he could not suggest a diagnosis other than Stroke for his symptoms.

The LAS and 111 operate using two different diagnostic systems. The LAS uses the Medical Priority Dispatch System (MPDS), (sometimes referred to as the Advanced Medical Priority Dispatch System (AMPDS)) which is a unified system used to dispatch an appropriate response to medical emergencies, including detailed questions to the caller to ascertain the presumptive diagnosis. Pre-arrival instructions and advice are also given. 111 uses an alternative system called NHS Pathways. Nick said that the symptoms he had, might not have been recognised by either system, and he asked who actually makes decisions regarding the diagnostic criteria for Stroke and other conditions, and whether these systems have been upgraded since his experience of Stroke in November 2023.

Nick experienced no Hemiplegia (paralysis that affects only one side of the body), no face droop or speech alterations, and no loss of function in his arms or legs. Although he had lost half his field of vision, he was not aware of that, but in practice he had only retained the left side of his field of vision. He was unable to recognise letters or numbers.

The scan at the RLH showed that a large area of his brain was affected, and as a result had lost half his field of vision on the left side of his brain. He said that his medical knowledge and experience confirmed for him that he had suffered a stroke, regardless of the negative response from the LAS. He was also surprised that a video was not used to assist diagnosis (this is only possible when ambulance staff are present at the scene).

The BE-FAST (Balance, Eyes, Face, Arm, Speech, Time) is an enhanced test to identify stroke and reduce the proportion of strokes missed using the FAST mnemonic, but the BE-FAST algorithm is not used by the LAS.

Of patients with Ischemic Stroke, with symptoms potentially amenable to acute intervention, up to 20% are not identified using the FAST test. The inclusion of gait/leg and visual symptoms leads to a reduction of missed strokes. The BE-FAST test works for double vision and for loss of vision, but it may not pick up the impact of having small emboli in the arteries but it does reduce false negative tests from 14% down to 4.4%, and may also be able to identify posterior strokes (which Nick did not have).

Ischaemic Strokes occur when the blood supply is cut off to part of the brain and account for the majority of Strokes. The blocked blood flow in an ischaemic Stroke may be caused by a blood clot or by atherosclerosis, a disease which causes narrowing of the arteries over time.

Embolic Strokes are usually caused by a blood clot (Embolus) that forms elsewhere in the body and travels through the bloodstream to the brain. Embolic Strokes often result from heart disease or heart surgery and occur rapidly and without any warning signs.

Nick said that the system did not enable the experience of the patient or carer to be heard, and was surprised that Dr Wrigley's response was that if a clinician called 999, they would be prioritised, when it is the symptoms rather than professional status that is the key concern in this case.

Dr Wrigley explained that there are two different processes which may involve an HCP being part of an emergency 999 call being made.

If a GP / HCP sees a patient, during a professional consultation, then they can request an ambulance for their patient based on their clinical assessment. In this case the GP/HCP will request an ambulance in a clinically appropriate timeframe – this might result

in a higher priority than if they have been through a formal triage assessment. This reflects the fact that the GP / HCP has assessed the patient and is using their clinical knowledge and taking clinical responsibility for the patient whilst they are waiting for the ambulance to arrive in the timescale they have requested.

The other situation (in the case of Nick) is where the patient or relative is a registered HCP. This would not override the triage priority but, if an HCP is on scene with a patient (but not clinically responsible for the patient), then in future, wherever possible, the caller should be passed to the Clinical Hub for enhanced clinical assessment to gather further information – **this action has been completed**. See also Appendix 1 - LAS response to concerns about hearing the voice of patients and carers.

Nick reflected on the risk to patients with the symptoms of Stroke that he had experienced, and the harm many patients may have suffered if their symptoms were not recognised, or dismissed by poorly trained call handlers and the algorithms they use. Although the 111 route may have been a better diagnostic system, the potential harm suffered by patients who have a stroke, due to the delay of going through two parallel systems could be catastrophic. He emphasised the importance of more effective training for call handlers and better use of the Clinical Hub (CHUB) within the Emergency Operations Centre, so that call handlers can immediately refer to clinical experts if they face uncertainty about the outcome of an algorithmic assessment.

Nick said that in his case, because he was a clinician, Dr Wrigley did arrange for an evaluation to be carried out, but it is not done routinely, except for clinicians or where a complaint has been made.

LAS Response: The LAS Quality Assurance (QA) team undertake routine audits of 1% of all 999 calls. In addition, QA is undertaken for <u>any</u> case where a concern or query is raised as is the case here. Where learning is identified we will establish improvement methodologies to reduce likelihood and improve outcomes either on an individual or organisational basis.

What is missing in the NHS Emergency Care System?
There is strong evidence of under-diagnosis of Stroke, which may be made worse by the failure of the LAS to use the BE-FAST test.
There are three types of Stroke:
- Ischaemic - narrowed blood vessel
- Haemorrhagic – acute bleed
- Embolic – clots from other parts of the body enter the brain. The clots may remain or be dissipated as happened in Nick's case.

There is also a risk of over-diagnosis of Stroke if the techniques used for diagnosis are inadequate. Nick asked who can make changes to the diagnostic method for identification of stroke and how basic problems can be resolved, e.g. the training of call handlers to make sure they refer patients to clinicians if there is any doubt about diagnosis? Nick said that listening to patients is fundamental in getting the system working more effectively, and he also referred to the MPDS system used in the UK since 1979, which is run by a USA company, and which may be too remote to influence regarding new diagnostic criteria.

Major questions raised by Nick were:
- Who can change the diagnostic system and introduce BE-FAST and better contact with Clinicians?
- Why is the system so unresponsive when clear and obvious shortcomings are brought to the attention of management?
- Are call handlers being adequately trained?
- How many strokes are missed as a result of system failures?
- How is the work of call handlers evaluated versus diagnosis?
- Is there a risk of over-diagnosis?
- How can Paramedics be more involved in diagnosis of Stroke?

QUESTIONS & ANSWERS

1) **Malcolm Alexander:**
Karen, do you think a major problem is that the system you experienced with the ambulance services was too bureaucratic, and that this caused the symptoms described by you not to be taken seriously, because the symptoms didn't fit into the algorithm which is used nationally and internationally?

KK replied: The call handler (CH) didn't seem to understand the significance of the symptoms I was describing and I assumed this was due to inadequate training. I felt that I wasn't being taken seriously. I explained that Nick was a GP, knew the symptoms of stroke and had just been discharged from hospital following two heart attacks and his main symptom was that he was unable to read. I told the CH that Nick knew the symptom was of serious concern. The CH's interaction seemed 'robotic', I tried twice to explain Nick's symptoms but couldn't get an appropriate response. All patients should get equal care including clinicians, but the LAS now seems to want to give priority to clinicians who phone 999.

LAS Response: There are 2 separate processes. Doctors who call us for a patient they hold clinical responsibility for are able to assign a clinically appropriate response timeframe via a separate process. In the case of 999 triage, all calls are treated equally and listening to the caller or patient is very important. Dr Wrigley has committed to ensuring where a clinician is on scene and a call is made for them or someone who they do not normally hold clinical responsibility for i.e. friend or relative, that a clinical conversation will be facilitated where possible. It was acknowledged by LAS that listening to the caller is absolutely essential and as explained earlier this has been reviewed and new processes implemented to enable the call handlers to get urgent support.

2) **Alan Alexander:**
If a patient calls 999, can they ask to speak to Clinician/Supervisor/Manager if they are dissatisfied with the response to their clinical symptoms from the CH after algorithmic diagnosis.

NM – Nick said he had worked in the LAS Clinical Cell during the LAS strike, so is aware of the way the CH and clinicians co-operate. There may be a range of clinicians in the EOC e.g. GPs, mental health professionals and paediatricians. The patient is unlikely to know if a clinician is available in the EOC to whom they can discuss escalation. If they asked to speak to a clinician this may be possible, but it is not how the 999 system usually works. In this case, there was no escalation to the Clinical Hub.

The algorithm seems to be presented as if it were more accurate in diagnosis than clinicians, but this is not the case. Algorithms are failing patients because there are many conditions that they cannot accurately diagnose. Maybe after 20 years of AI development they will be much better, but only if they can be adjusted to be responsive to their shortcomings.

LAS Response: We were privileged to have Nick with us during industrial action. However, arrangements during industrial action were VERY different to our normal day to day operations in the CHUB given the degree of risk and uncertainty when staff were taking action. We do usually have Paramedics, Nurses and Mental Health nurses with us in the CHUB and are trialling GPs/ED Consultants but this is not yet formally established 24/7.

3) **Coral Jones** asked how effective and fast the Homerton Hospital A&E were once NM and KK arrived by taxi?

   <u>NM/KM</u> – Very fast. From reception to ambulance in about 15 minutes. Told reception Nick had just come out of Bart's following a heart attack and that he couldn't read and had had a stroke. They pulled him through the system very quickly and he was transferred to the Royal London Hospital by ambulance.

4) **Miriam Beeks** said she was surprised by the response of the LAS, because the NHS Aphasia website makes it very clear that the sudden inability to read is Receptive Aphasia and the inability to write is Expressive Aphasia. Whilst recognising that these symptoms can't always be included in the FAST test, that the inability to read as a symptom of Stroke was very obvious. https://www.nhs.uk/conditions/Aphasia/symptoms/

   Note: The definition of Aphasia has been broadened and would include Alexia. Technically, Dr Mann had 'Posterior Alexia'. This would not have been included in the FAST algorithm. If LAS had used a 'BE-FAST' algorithm it may have been detected. Mike Ward indicated that "inability to read" should trigger a stroke response in the NHS-Pathways (LAS 111) algorithm, but would not be included in the (LAS 999) MPDS algorithm.

   KK said that these issues have been raised with Dr Fenella Wrigley and (a written response to this question and others will be available after the meeting). Fenella Wrigley confirmed that all LAS clinicians have been made aware of the different types of Aphasia and the associated symptoms. But are CHs aware? The algorithm needs to be updated and CHs made aware of the importance of referring patients with Receptive Aphasia to a Clinician or send an ambulance immediately.

   LAS Response: Dr Wrigley has confirmed that the issue had been raised with the authors of both NHS Pathways and MPDS through the appropriate national groups requesting a review of their algorithms.

5) **Cynthia White** described her husband's massive stroke, and as his carer the great difficulty in knowing what to do, and how to think rationally in this situation when you feel panic, tense and worried, e.g. whether to call 111 or 999. She suggested that guidance for carers whose loved one suffers a Stroke would be very valuable, especially in relation to getting the right care at the nearest Stroke centre. She suggested that guidance for carers should be

produced, which highlights the symptoms, including the inability to read, and helps the carers to know how to emphasise to 999 the importance of the various symptoms that the person might suffer.

MA said he would raise this issue with the Stroke Association and distribute the Stroke Association FAST leaflet. Agreed to emphasise the importance of inability to read (receptive Aphasia). MA to discuss with Cynthia distribution of Stroke leaflet though the Older Persons Reference Group and Age UK.

Note: Inability to read is Alexia, whereas Receptive Aphasia is the inability to comprehend or use spoken language. It would be interesting to know how LAS algorithms pick up and respond to frank Receptive Aphasia).

6) **Terry Stewart** said he had a stroke in 2009 and the LAS Call Centre was excellent. He expressed great concern about the problems in the LAS call-centre, i.e. the failure to take notice of Dr Mann's condition when it was clear to him what his diagnosis was and was conveyed clearly to the call handler by KK. He asked if there was evidence that policies had changed in the LAS which had affected the quality of Call Handler staff training? He asked if all staff now receive appropriate training before starting work in the call centre and why KK was told to go to 111 when evidence of stroke was so clear?

NM replied that it was his belief that the training of CHs had reduced following the increasing use of algorithms by Call Centre staff; but he could not verify this. He added that it will be a long journey for algorithms to be as effective as properly trained clinicians and call handlers, and it appears that effective training is diminishing, and algorithms are being seen as an appropriate alternative to well trained staff. Nick said that in his case, waking up and being unable to read was clearly a symptom of Stroke, and that it was common sense to provide emergency care in this scenario. He added that in 'good practice' a conversation between the patient/carer, the Call Handler and then a Clinician should have taken place.

LAS Response: We also need to recognise that all 999 call centres use triage tools and calls are taken by non-clinicians and has been this way for many years. Our training is consistent, regularly updated in line with learning from both incidents and examples of excellence both in LAS and nationally and that our QA demonstrates this is of a consistently high standard. There is no evidence of poor training – we are an accredited centre of excellence for call handling

7) **Courtney Grant:** Asked if a major problem for the LAS is that call-handlers clinicians and despatchers are not adequately co-located? He asked how the LAS assesses the effectiveness and performance of algorithms. Courtney said that as a Human Factors specialist he was very concerned that greater automation of systems creates excessive trust in those systems and potential harm to patients. Courtney referred to an analysis of this situation in a paper called the Ironies of Automation.
https://humanfactors101.com/2020/05/24/the-ironies-of-automation/

Courtney described the death of his brother in September 2023 from a head injury. In this case there was a severe delay in response to the Cat 2 call and problems with operation of the LAS Clinical Hub. Courtney said that the severity of his brother's condition was not identified correctly until it was too late, and felt that this too was caused by the use of algorithms, which don't adequately identify the severity of the illness, and in some cases delay despatch of an ambulance to the sickest patients. He described the failure of the Clinical Hub to act effectively in his brother's case.

NM confirmed that the Clinical Hub is located in the Emergency Operations Centre and co-located with the call handlers. He added: As call handlers are extraordinarily pressured and in light of Courtney's comments and the paper about over reliance on technology, it seems unlikely that 'sudden inability to read' and other symptoms would ever get to clinicians within LAS.

8) **Mike Ward** is a Senior Manager in the Emergency Operation Centre at the LAS. In response to Terry and Nick's comment (item 6), he apologised for the poor service that NM had received and assured the meeting that there had been no reduction in training for CHs or Call Co-ordinators. He said that the algorithmic system used by CH was monitored by non-clinical assessors to ensure it was working effectively. Mike said that the LAS has collocated senior clinicians with despatchers to provide face-to-face leadership and support when making clinical decisions. In NM's case, the decision was to refer to 111, where there is a group of clinicians who would have made a full clinical assessment of his clinical needs

NM replied that in cases of stroke where rapid responses are required, that going through 111 would have caused additional delay in getting to the specialist Stroke centre, because of the time it would have taken for 111 to answer, the time spent with a CH and clinician, and the time to get an ambulance. The delay could have caused him severe harm. He asked how

many dropped calls there are daily in the EOC that could have resulted in serious harm to patients, and how many calls should have had a clinical response in the EOC, but did not? NM said it should have been obvious that as he couldn't read, that he was suffering a stroke, but the algorithm and the LAS system failed him. He asked whether the algorithm had changed in any ways since his contact with Dr Fenella Wrigley? He felt that a quick-fix would not be possible because the system is so bureaucratic.

KK said that she often hears negative things said about the performance of 111 and they were not going to risk harm due to delay. Speed is essential in Strokes. She said that in Nick's case the cab came in 10 minutes and once the LAS had failed to respond appropriately, that the cab was going to be faster than the 111 service, although the cab couldn't provide additional support in case of any deterioration in Nick's condition. She added that there appeared to be many whole system weaknesses in the emergency care system, which appeared to be failing some patients, because it took too long to bring about changes required to the algorithm.

9) **Mike Ward** explained that the LAS doesn't own the software for MPDS, it is purchased as a software package from the International Academy of Emergency Despatch (IAED) a USA company. The algorithm can only be changed with the agreement of IAED. The LAS often presents the case for change to the algorithm and IAED build a data picture and undertake analysis of the request, and if they agree roll out the change internationally. It does take a long time to change the algorithm and the LAS would like to see the process speeded up. The LAS can also make representations for change to NHS England, the Clinical Coding Review Group, national Stroke teams and networks and ECPAG – the Emergency Call Prioritisation Advisory Group. Mike said that NHS Pathways does include the lack of ability to read as a symptom of Stroke.

Note: It is the case that 2 different algorithms are used by the LAS that provide different responses to the symptom 'sudden inability to read'. The outcome of a presumptive Stroke call to the LAS will be determined by whether 999 (MPDS) or 111 (NHS Pathways) algorithm is followed in response to the call.

LAS Response: No approved tool for the non-clinical triage of a 999 or 111 call in England identifies sudden inability to read (that is not due to visual disturbance) as a potential Stroke.

10) **Sister Josephine** thanked Nick and Karen for their excellent presentations. She said what happened to Nick, could be typical of what happens to many other patients if they are not listened to and not heard when they are seriously ill. She said that ignoring what Karen had said about Nick just coming out of hospital after two heart attacks was completely unacceptable.

She asked if there is any research to ascertain how many patients who suffer strokes are not correctly diagnosed as a result of faults with the algorithm, and what harm they may suffer as a result of delay. Sister Josephine also asked if a formal apology had been given to Nick by the LAS (Duty of Candour), and expressed her gratitude to Nick and Karen for joining the meeting of the Patients' Forum.

LAS Response: The Chief Medical Officer, Dr Fenella Wrigley, has formally apologised to both Nick and Karen on a TEAMs call on 18th January 2024. This was done verbally.

Sister Josephine said that changes to the algorithm should be carried out immediately, not wait for committees to decide a change which is so obviously needed, and changes to the training of CHs should be carried out immediately as well, and this should include empathy and improved communications. Sister Josephine thanked Nick and Karen for presenting their story to the Forum and Mike for explaining in detail how the system works and what needs to be improved.

Mike Ward said that he and James Lafferty are jointly the senior managers for the clinical hub in the EOC and they have doubled the number of clinicians in EOC. The future despatch model requires clinicians and CHs to be co-located and ensures an enhanced model in which CHs have direct access to clinicians and supervisors. He thanked Nick and Karen for presenting to the Patients' Forum and giving the LAS the opportunity to learn from their experience. He acknowledged that the Clinical Hub was not involved when Karen called 999 regarding Nick's Stroke. Mike added that another LAS development was the focus on emergency calls of a very specific nature, e.g. those from clinicians.

Nick Mann said that when they called 999 that it was obvious we knew what we were talking about. He expressed concern that other patients with small emboli or other critical symptoms were being missed and felt that the lack of competence of the algorithm was stark, and that as more reliance was placed on the algorithm, that effective clinical diagnosis will be dumbed down. He said

it is essential for the LAS to learn from patients' experience and that he and Karen want to support improvements to LAS services, not criticise them.

11) **Heggy Wyatt** said that a major cause of over reliance on algorithms was the closure of NHS Direct in 2014. She described working there as a Band 6 Nurse for 3 years, and the 50:50 ratio of nurses and call handlers who worked together in the same room. Call handlers could flash up a request for clinical input when the algorithm was not working for particular patients. She said that B6 Nurses would have spotted the sudden onset of a neurological deficit. Concern was expressed that the GP hubs planned for NW London may generate further delays and diagnostic errors.

12) **Coral Jones** spoke about the dehumanisation of diagnostic medicine through the use of algorithms instead of direct contact between patient and doctor. She said that what happened to Nick is a warning about how computerised systems will increasingly fail patients and how the NHS is moving to diagnostic models that replace experienced doctors with computer programmes. She said that the 111 system was another example of how patients are being separated from the clinical expertise required for effective diagnosis. Coral said that GPs were the best clinicians for patient triage, not 'physician associates', who are not medically trained and that what happened to Nick was an example of the failures that dehumanised systems will increasingly inflict upon patients.

13) **Nick Mann** thanked Mike Ward and James Lafferty for attending the meeting, listening to his experience of LAS care, and describing the improvements happening in the LAS Clinical Hub. He suggested it would take more than 20 years before AI systems could be trusted to provide accurate diagnosis of patients' conditions. Nick expressed concerns about harmful recent developments in the NHS, e.g. the Babylon GP service, Physician Associates and the plan for NW London GP Hubs.

14) **Karen Kennedy** referred to the mechanisation and dehumanising of medical care. She said that when using the 999 system following Nick's stroke it felt like she was talking to an algorithm. She called for NHS developments to be sensitive to the needs and experiences of patients, rather than the dumbing-down of patients' needs and the provision of apps instead of caring clinicians.

Note: LAS is commissioned to provide 111 services in the following London areas: North Central, North East, North West, South East and part of South West.

RESPONSE FROM DR FENELLA WRIGLEY, LAS CHIEF MEDICAL OFFICER TO QUESTIONS FROM

NICK AND KAREN

1) WHY ISN'T 'SUDDEN INABILITY TO READ' A CATEGORY 2 ALERT?

The majority of acute Stroke patients present with signs that can be identified via the Face Arms Speech Test (FAST). Atypical presentations are inherently challenging to identify at the initial stage. Patients suffering strokes can present with a wide range of presenting symptoms including falls, fits, dizziness, headaches etc. These cases may not be picked up in the initial triage and so an additional clinical assessment helps us to identify these patients.

The additional clinical assessment is done by either our 999 Clinical Hub (by Paramedics or Nurses) or through LAS 111 (which has a multi-disciplinary team including advanced clinical practitioners and GPs). This enables us to provide a more individualised response, which might be an ambulance, a specialist response e.g. mental health car / urgent care car or it might enable us to make a referral to services closer to the patient's home. It is also important for us to ensure that patients with complex presentations or specific illnesses receive the right ambulance response.

If the patient or caller is asked to ring 111 and an ambulance is required, then the patient is immediately transferred back into the ambulance dispatch queue, at the priority level indicated by the additional clinical assessment.

Stroke patients are designated as category 2 (maximum 18 minutes to arrival time) where the symptoms are identified during the initial 999 call, and the symptoms started within the nationally agreed timeframe.

2) HOW ARE CHANGES TO DIAGNOSTIC ALGORITHMS MADE BY AMBULANCE SERVICES?

The London Ambulance Service 999 emergency triage tool is the Medical Priority Dispatch System (MPDS). This triage tool is built on having tested hundreds of millions of calls since 1979. MPDS includes 26 protocols (with hundreds of subcategories) that are continually updated based on recommendations and research. 999 calls triaged via this tool will generate a corresponding determinant code. Each of these codes have an associated ambulance response category which is agreed by NHS England based on the review of very large numbers of calls.

There are various national clinical leadership and steering groups tasked to oversee developments and changes within 999 emergency triage. These groups comprise of Subject Matter Experts and ambulance service representatives who share learning from incidents, clinical audit and patient experience.

Where an ambulance service identifies, through learning, there may be a need to review a triage protocol or prioritisation this is raised through the following process:

- **Triage Protocol concern**

 - A local ambulance service or Coroner or expert group identifies a concern with a triage protocol.

- The recommendation for review is raised to NHS Pathways and MPDS teams – they will decide about any changes to their triage tool. NHS England clinical coding groups are also informed.

 - The request for change goes through expert clinical groups, governance groups, technical groups and when the change is made it is changed for all users (for MPDS this would be shared internationally, and for NHS Pathways it would be shared in England).

- **Request for review of ambulance priority for a particular determinant code (patient group)**

- A request for a change to ambulance priority level for a particular determinant code (called re-categorisation) is made to the NHSE national coding group.

- The national coding group gathers information about the request from other ambulance services and discusses it with NHS Pathways and MPDS

- If it is agreed there should be a change to the priority of a 'determinant' then the recommendation is made to the National Emergency Call Prioritisation Advisory Group (ECPAG)

- If approved, then all ambulance services make the change by an agreed date

The LAS has a close relationship with the International Academies of Emergency Dispatch and NHS Pathways and works collaboratively where evidence indicates a protocol/determinant change or where a further development may be required.

Since Dr Mann's case came to light, the concern that this symptom of a Stroke is not being picked up through LAS triage has been raised to:

- o MPDS
- o NHS Pathways
- o National Coding Group

- o Stroke Clinical Network Co-Clinical Directors – London Region (response shared with Dr Mann)
- o National Stroke Director

3) WHAT IS IN PLACE TO MONITOR THE NEED FOR ALGORITHMIC CHANGES TO THE CATEGORISING OF SYMPTOMS?

The LAS Clinical Audit and Research Unit (CARG) produces a Stroke Registry, which holds clinical information extracted from the LAS Patient Electronic Patient Care Records (ePCR), which are completed on-scene by the attending Clinicians, and operational data collected from the Emergency Operations Centre (EOC) Call Logs and vehicle Mobile Data Terminals (MDTs).

Reports are shared internally and with national clinical audit and leadership groups for consideration. The learning is also shared internationally for product owners to review their triage tool and to make changes where required.

4) RESEARCH INTO THE USE OF THE 'FAST' TEST CALCULATED THAT ONE ON FIVE PATIENTS WITH STROKES ARE ROUTINELY MISSED.

The evidence from telephone assessments from the International Academies of Medical Dispatch is that the Stroke diagnostic tool has been proven, through research, to identify more than twice as many strokes as medics on scene):

Note: The IAED link from Dr Wrigley links only to the front page of the IAED website. Research from 2014 Randomised Control Trial at Karolinska Institute indicates that the opposite is true: Emergency Ambulance staff are significantly more likely, not less likely, to correctly identify a Stroke: https://pubmed.ncbi.nlm.nih.gov/24576912/ https://www.emergencydispatch.org/home

In London we have, and continue, to work with the stroke networks to ensure we identify as many Strokes as possible. This includes using additional clinical assessment:

- For ambulance crews on scene in some ICSs the use of video triage is available, which allows a crew to share symptoms with staff in the EOC clinical hub, if they suspect a new loss of function is possible; even if the patient is FAST negative.
- For all clinicians within the LAS (telephone and face-to-face): we have shared case examples with our clinicians to highlight less common presentations of stroke and emphasise the need to factor in the testimony of both the patient and/or their carer.

5) EXTRA AMBULANCE CONVEYANCING – PATIENTS WITH STROKE SYMPTOMS MAY BE TAKEN TO HOMERTON A&E, THEN TO THE ROYAL LONDON HOSPITAL

The LAS monitors the conveyance of Stroke patients directly to HyperAcute Stroke Units. The annual Stroke audit for 2022-23 showed 99.6% of patients were conveyed to the right destination first time. The data for 2023 -24 shows over 99% of patients have been conveyed to the correct destination.

If a patient requires transfer from an ED to a HASU, then this is a Category 2 transfer if they are within the timeframe for thrombolysis or thrombectomy.

OUR RECOMMENDATIONS TO THE LONDON AMBULANCE SERVICE

1) As a matter of urgency the MPDS algorithm must be amended to include "Sudden inability to read" as a Stroke symptom.

2) Action must be taken to ensure that MPDS and 111 NHS Pathways recognise the same symptoms in the diagnosis of Stroke.

3) Sudden Inability to read must be regarded as a Stroke symptom equal in status to other symptoms included in FAST and BE-FAST.

4) The LAS must adopt the BE-FAST algorithm for standard use, in view of the evidence that it reduces Strokes missed by FAST from 14% to 4.4%. https://pubmed.ncbi.nlm.nih.gov/28082668/

5) Call Handlers in LAS Emergency Operations Centres, must receive additional training regarding their response to Stroke symptoms, including 'sudden inability to read' and this training should be carried out together with other staff in the Clinical Hub.

6) Front line LAS staff should be trained in the use of video assessment techniques to assist diagnosis of Stroke.

7) Training of all clinical staff in the LAS must ensure that face to face clinical assessment is seen as the most effective way of diagnosing a Stroke, and that the FAST test is no longer seen as the highest level of diagnostic practice in Stroke diagnosis. https://pubmed.ncbi.nlm.nih.gov/24576912/

8) Front line staff and their managers must be trained in Human Factors to enhance their awareness that algorithms can lead to 'over-dependence' on them as a diagnostic tool, and that Clinicians may become over-reliant on such algorithms, causing important symptoms and diagnoses to be missed.

9) Multiple organisations must collaborate and agree to alterations or updating of algorithms. These remote organisations must operate within a clear and efficient chain of command and communication system, to quickly enable necessary changes to occur.

Actions so far taken by DR FENELLA WRIGLEY, LAS Chief Medical Officer to improve recognition of diagnostic criteria for stroke

Following the meeting between Dr Mann, Karen Kennedy and Dr Fenella Wrigley, Chief Medical Officer of the LAS on 18th January 2024, a significant amount of work has been undertaken to share learning and request changes. At the meeting on 18th January the LAS CMO committed to taking Dr Mann's concerns to national groups (re Stroke and triage tools). Some of the meetings are quarterly and Dr Wrigley has advised these changes can take quite some time, but she has raised them to all the appropriate groups. There are national clinical reference groups for NHS Pathways and MPDS, which each have an ambulance representative and LAS are utilising this route.

The actions which have been taken include:

- Request made via the national clinical coding group
- Highlighting the case to the MPDS and NHS Pathways teams
- New processes in EOC for call handlers to highlight concerns to clinicians
- Co-locating clinicians with dispatchers to provide support
- Increasing capacity in the 999 Clinical Hub and 111 IUC so if a patient requires a rapid clinical assessment this is done in a timely way
- Sharing the case with regional and national stroke leads
- Sharing the case with clinicians across urgent and emergency care
- Dr Wrigley has invited Dr Mann to share his story with the LAS Board.
- Dr Mann has been invited to visit the LAS call centre and spend some time to see the changes so far made, when he feels well enough to do so.

CONCLUSION FROM KAREN KENNEDY

Karen Kennedy said: I will remain acutely aware that the LAS failed to provide an emergency ambulance when it was desperately needed, because of an adherence to a formulaic response, rather than an empathetic listening to what I was telling them. Had I not taken Nick by taxi to A&E, the outcome could have been a disaster for us. It is deeply disturbing that such a disaster could happen to others at any time. I sincerely hope that the LAS learns from what happened to us and takes action to implement major changes to their diagnostic system. The LAS needs an engaged, intelligent human response with call handlers actively listening, rather than following an algorithm that could lose many lives. We have been very fortunate that the development of Nick's symptoms at that time and his recovery since have left him relatively well and unscathed.

DUTY OF CANDOUR

Dr Wrigley would like to reiterate on behalf of the LAS her apologies for the failings Nick and Karen experienced at a time when they needed help from LAS. She recognises how difficult talking about the experience was and is very grateful to them both for sharing their story so LAS can continue to learn and improve.

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APPENDICES

APPENDIX ONE: HEARING THE VOICE OF PATIENTS, CARERS AND CLINICIANS

Nick Mann said that the system did not enable the experience of the patient or carer to be heard, and was surprised that Dr Wrigley's response was that if a clinician called 999, they would be prioritised, when it is the symptoms rather than professional status that is the key concern in this case.

Dr Fenella Wrigley agreed that listening to the caller, particularly if they were someone with enhanced knowledge, e.g. a healthcare professional, was very important. She said that the LAS is committed to ensuring that should this happen, that the LAS should, wherever possible, pass the caller to a clinician for a further assessment. Fenella explained:

If a GP or other HCP sees a patient with stroke symptoms, they can request an ambulance for the patient based on their clinical assessment – this might result in a higher priority as the HCP has assessed the patient and is using their clinical knowledge to request an ambulance in a clinically appropriate timeframe and they are taking clinical responsibility for this decision. The other situation (as in the case of Nick) is where the patient or relative is a registered HCP. This would not override the triage priority, but we have to ensure that the caller is being listened to.

1. Karen explained to the call handler that Nick was a doctor and knew he was having a stroke
2. Call handler did not escalate this for further advice
3. Dr Wrigley acknowledged the LAS needed to make changes to ensure the voice of patients /carers was heard well and that this was very important when a diagnosis was being suggested
4. Dr Wrigley committed to ensuring that, if an HCP is on scene with a patient (but not clinically responsible for the patient, then the call should, wherever possible, be passed to the Clinical Hub for enhanced clinical assessment to gather further information – this action has been completed.

Fenella added: The immediate action we have in place is the process of rapid clinical assessment. This means that a clinical assessment happens very quickly and we are ensuring that clinicians are aware of the loss of ability to read as a stroke symptom. We have also reiterated that, where a caller or patient, is a clinician, early transfer to a clinician should be considered. This will help mitigate the risk Nick experienced of the triage tool not recognising what you were clinically explaining

APPENDIX TWO: Statement by Dr Nick Mann regarding the LAS response to Stroke Diagnosis

Dear Malcolm,

I should like to comment further regarding the PFLAS meeting with Fionna Moore. Whilst I found the meeting overall both informative and instructive, I remain concerned that 'high level' strategic plans have not kept pace with the reality of changes to patients' actual experiences of medical pathways.

As an experienced medical doctor, I covered some shifts in the LAS Control Centre during the strike. My main duties were to triage lists of category 2 calls according to either the dispatch of urgent ambulances to patients, or the downgrading of responses, which often involved re-directing patients to urgent community response pathways (alternative care pathways), using bespoke software between two separate systems.

It was notable that many of the so-called new models of care for 'urgent community response' were either unavailable, or available but did not respond, or re-directed patients to other services at inappropriate times. In many cases, much time and effort resulted in calling standard GP services as the 'urgent community response' services did not function appropriately.

Experienced LAS Doctors, including GPs and Paediatricians have been used as a 'new model of care' to supplement less experienced LAS 'Call Handlers', increasingly using algorithms to triage urgent 999 patients. In addition to the costly use of medical clinicians, it is possible to video call patients to obtain more detailed audio or visual information.

Little reliable detail of actual changes to LAS pathways, resulting in careful detailed analysis of changes to medical pathways and outcomes exists. I will give two real-life examples from my own experience.

Firstly, the latter changes have been made in the context of several years of rising and unsafe levels of Category 2 calls, e.g. patients requiring a Category 2 response, now routinely experience average 40-minute waits instead of 18-minute safe maximum waits. How many patients are the LAS excluding from their performance data, due to patients choosing to opt to attend A&E by taxi, instead of calling an ambulance?

I recently opted to be driven to A+E during a heart attack because the wait for an ambulance was likely to be very long, putting my health at severe risk. Secondly, I was recently refused a 999 ambulance during an acute Stroke, following a call to a poorly trained call handler who was using an algorithm. Despite telling the call handler that I was a doctor and knew that I had had a Stroke, I was refused an ambulance and was told that I should call 111.

During the Patients' Forum meeting, Dr Moore suggested that Call Handlers could improve response times by using video calls during patient consultation. However, the FAST algorithm failed to pick up my parietal lobe Stroke and a video call would:

a) Require a Paramedic to have attended the patient on-scene, and

b) Not have increased the likelihood of detection over an experienced doctor, directly informing 999 staff that I had had a Stroke. What is clear is that the use of algorithms is a poor substitute for an experienced and well-trained call handler, nurse, doctor or paramedic. The benefits of algorithms in medical care have been poorly examined and under-evaluated. Its benefit is that it is cheaper.

The reality is that technology's claims for medical algorithms and AI have been over-claimed and often dangerously under-perform. There are clear examples of this with 'chatbot' technology.

The rush to 'transform' expert medical diagnosis into 'technologies' comes primarily from consultancies and industry, instead of development from medical experts working with the developers of this technology. LAS is a poorer service for patients as a result, and years will be spent compensating simply for the loss of trained individuals in medical care.

Yours sincerely,
Dr Nick Mann

APPENDIX THREE: APHASIA AND ALEXIA

RECEPTIVE APHASIA - A person with receptive Aphasia experiences difficulty understanding things they hear or read. They may also have difficulty interpreting gestures, drawings, numbers and pictures. This can affect everyday activities such as reading an email, managing finances, having conversations, listening to the radio, or following TV programmes. People with receptive Aphasia may have some of the following signs and symptoms:

- difficulty understanding what people say
- difficulty understanding written words
- misinterpreting the meaning of words, gestures, pictures or drawings
- giving responses that may not make sense if they've misunderstood questions or comments
- not being aware of their difficulties with understanding, or their own speech errors

ALEXIA - DEFINITION

- **Alexia is an *acquired* deficit in the ability to interpret written language; does not refer to those impairments (congenital or acquired early in life) which prevent the normal acquisition of reading skills (which are considered *developmental dyslexia* or simply *dyslexia*)**

Note: Some differences in definitions exist between categorisations of types of Alexia: https://www.ncbi.nlm.nih.gov/books/NBK557669/

HISTORY

- Recognized for centuries, but became a significant problem only in 20th century, when literacy expectations increased considerably.
- Origin of current concept of alexia stems from two case reports by Dejerine (1891, 1892); cases represent what has become known as central alexia and posterior alexia.
- Dejerine's alexia classification fell out of use until repopularized by Geschwind (1
- 962)

MAJOR SYNDROMES (3 types)

Central Alexia (Alexia with Agraphia)

- Basic clinical features:
    - severe (not necessarily total) disturbance of both reading and writing
    - preserved ability to copy written language, but in slavish and non-comprehended manner
    - loss of ability to name letters, to comprehend spelled words, or to read out loud
- Often accompanied by other neurobehavioral disorders including:
    - Aphasia
    - components of Gerstmann Syndrome (finger agnosia, right-left confusion, acalculia, and agraphia)
    - some degree of hemisensory loss and/or right homonymous visual field deficit
- Locus of pathology includes inferior parietal lobe of language dominant hemisphere, centering on angular gyrus; typically damage to both cortex and white matter
- Causes most often from occlusion of MCA or distal branches (inferior parietal lobe); may also be caused by neoplastic lesions
- Other common names: semantic alexia, parieto-temporal alexia, total (literal and verbal) alexia, letter and word blindness, surface alexia

Posterior Alexia (Alexia without Agraphia)

- Basic clinical features:
    - Individual can comprehend written material
    - Writing is almost or totally w/in normal limits BUT can't comprehend what is written
    - Easily write but have more trouble copying written language
- With practice, can learn to read most letters out loud; words can then be spelled out loud and recognized auditorially
- In most cases, associated neurological findings include:
    - right homonymous hemianopia
    - colour naming disturbance
- Pathology is typically infarction of left posterior artery territory, including splenium of CC (spares angular gyrus)
- Disconnects visual info from language cortex

- Other common names: verbal alexia, visual alexia, pure alexia, occipital alexia, associative alexia

Anterior Alexia (Frontal Alexia)

- More recently discovered so also known as the "Third Alexia"
- Basic clinical features:
  - Great difficulty naming individual letters of alphabet but can recognize some written words
  - Severe agraphia; ability to copy written language poor
  - Comprehend some spelled words, but poor at spelling aloud
  - Recognize some semantically meaningful words but fail to comprehend the grammatically significant function words – *Agrammatism of written language*
- Accompanying neuro findings:
  - Right hemiplegia
  - Nonfluent Aphasia
  - May include unilateral sensory and/or visual-field neglect
- Pathology is typically left frontal area
- Other common names: literal alexia, letter blindness

Table Summary of Three Major Syndromes

	POSTERIOR	CENTRAL	ANTERIOR
Written Language			
Reading	Verbal alexia	Total alexia	Literal alexia
Writing to dictation	No agraphia	Severe agraphia	Severe Agraphia
Copying	Slavish	Slavish	Poor, clumsy, omissions
Letter naming	Relatively ok	Severe letter anomia	Severe letter anomia
Comp. of spelled words	Good	Failed	Some success

Spelling aloud	Good	Failed	Poor
Associated Findings			
Language output	Normal	Fluent Aphasia	Nonfluent Aphasia
Motor	No paresis	Mild paresis	Hemiplegia
Motor apraxia	None	Sometimes	Frequently present
Sensation	No problems	Often sensory loss	Mild sensory loss
Visual Fields	Right hemianopia	Sometimes hemianopia	Usually ok
Gerstmann syndrome	Absent	Frequent	Absent

APPENDIX FOUR: FAST TEST LEAFLET

The Face, Arm, Speech, Time (FAST) test can help you recognise the symptoms of a stroke

FAST

Facial weakness
Can the person smile?
Has their mouth or eye drooped?

Arm weakness
Can the person raise both arms?

Speech problems
Can the person speak clearly and
understand what you say?

Time
to call 999.

What are the symptoms of stroke?

- Sudden weakness or numbness of the face, arm or leg on one side of the body
- Sudden difficulty speaking or understanding spoken language
- Sudden loss or blurring of vision, in one or both eyes
- Sudden confusion
- Dizziness, unsteadiness or a sudden fall, especially with any of the other signs
- Sudden severe headache with no apparent cause

Why act FAST?

Stroke strikes every five minutes in the UK. It can happen to anyone, of any age, at any time. There is no way of knowing if symptoms will pass or get better when they first start, so you need to seek immediate medical help. A stroke is a medical emergency. Always dial 999. The quicker the person arrives at a specialist stroke unit, the quicker they will receive appropriate treatment.

It is critical that treatment is given quickly, to limit the impact on the brain.

If you suspect a stroke, act FAST and call 999

APPENDIX FIVE: GLOSSARY	
AI	Artificial Intelligence
A&E	Accident and Emergency Department
ACP	Alternative Care Pathway
AI	Artificial Intelligence – simulates human intelligence
BAME	Black, Asian and Minority Ethnic Groups
BE-FAST	BALANCE - EYES – FACE – ARM – SPEECH - TIME
CAD 2010	Computer Aided Despatch
CARU	Clinical Audit and Research Unit
CH	Call Handler
CHUB	Clinical Hub (within LAS Emergency Operations Centres)
ECPAG	Emergency Call Prioritisation Advisory Group
EOC	Emergency Operations Centre
ePCR	Electronic Patient Care Records
FAST	**Facial** weakness **Arm** weakness **Speech** problems **Time** to call 999
FRCEM	Fellow of the Royal College of Emergency Medicine
HASU	HyperAcute Stroke Unit.
HCP	Health Care Professional
IAED	International Academy of Emergency Despatch
ICS	Integrated Care System
LGPTQ	Lesbian, Gay, Bisexual, Transgender and Queer
MDTs	Mobile Data Terminals
MPDS	Medical Priority Dispatch System
NHSE	NHS England
TIA	Transient Ischaemic Attack – the same as a Stroke, but of limited duration and tissue damage; ongoing symptoms are a medical emergency
UCH	University College Hospital