Citizens’ Senate Meeting No 26 - 18/8/2020

Meeting notes: This is a summary, please listen to the recording if you would like more detail. The group gave consent to share the recording of the meeting.

Recording of meeting - Topic: Trevor Fernandes' Personal Meeting Room
Date: Aug 18, 2020 10:45 AM London
https://us02web.zoom.us/rec/share/25RaI7P3_UhOTI31z0KHdPEiNIv_X6a82nAe86BfzEmTPvhj6PHetGYyWP7EDXga
Access Password: ywe&du6C

Present: Fiona Carey, Kevin James, Paul Osman, Jeremy Dearling, Gillian Orves, Ann Nunn, Vicky Carr, Ann Marie Fordham, Michele Stewart, Patricia Ma, Sarah Coote, Rod Earp, Sarah Rae, Roy Johnson

1) The meeting was held on Zoom video conference. This was a 90min open session, with participants having control of mute / video. Members were invited to use the chat box for exchanging messages with the whole group, or privately to individuals. Time for Q & A was allowed following presentations. As we didn’t have a moderator for this session, we attended to questions as and when.

2) **Nick Clarke**, Principal Advisor, Eastern AHSN introduced himself to the group and presented the Mental Health portfolio - in particular, ADHD and Eating disorders, which was Eastern’s commitment to the national adoption programme. Mental Health is one of three priorities, the others are Cancer and rare diseases. These priorities are underpinned by the population’s need for supported living and ageing well. Nick went on to describe how the ADHD and Eating Disorders would be designed and delivered using the QbTest tool. Nick’s presentation can be found on the Citizens’ Senate website - https://www.eoecitizenssenate.org/previous-meeting-minutes

3) The group discussed the impact of the pandemic on our lives. Each person answered three questions: How has COVID impacted you, one thing COVID has taught you and was there anything positive gained from COVID. This agenda item required more time as it generated a lot of discussion. Whilst a few people coped reasonably well during the pandemic, some people found it extremely difficult, with many unintended consequences. We agreed that we should support each other by sharing experience and coping strategies.

4) **Paul Osman** shared his observation of his recent experience of the NHSE Patient Partner Voice online learning programme. This was a pilot which Paul thought would be beneficial in the longer term. Paul also shared his experience of his role as PPV on the National Cancer Alliance Patient Advisory Board in the East of England. He highlighted the four national priorities are: increased number of diagnostic centres, personalised care and support and the use of genome analysis and focused screening on high risk groups. The NHS response to COVID was to restore cancer operations and accelerated return to non COVID services. Paul observed that at a Cancer STP

meeting in Mid & South Essex, the 14, 30 and 62day targets were not met, even before the pandemic. Please see recording/transcript of the meeting to find out more.

5) **Gillian Orves** and **Vicky Carr** also shared their experience and highlighted the unacceptable decisions being taken regarding patient & public engagement at Ipswich Hospital user group. Far reaching change was made when Ipswich and Colchester merged to form East Suffolk and North Essex Foundation Trust, although changes were expected regarding patient experience. iHUG was in existence for 19years and was a very effective patient group. This was abandoned quite suddenly and without consultation, in spite of the group winning awards for patient experience. Gill is working with the system leaders and decision makers to explore alternative models of engagement, which may be equally effective, but time will tell. Please listen to the recording to hear more about this from Gill

6) **Szara Coote** was due to talk about Social Prescribing Link Workers in primary care, which is one of the five reimbursable roles to be implemented by 2021 and part of the Network Contract. Unfortunately, we ran out of time, so this item will be covered at the next meeting. Despite the positive campaign, Szara discovered that following a survey, 33% of link workers have already resigned due to lack of support and training. More on this next time, but please explore this at your individual GP practices and PPGs.

Actions:

We ended the meeting at 1pm (30mins late) and it was obvious that 90 min sessions were insufficient to cover our quarterly Citizens' Senate meetings. The group agreed:

- We would have monthly or 6 weekly meetings, with fewer items on each agenda, which will allow adequate time for everyone to share their observations and views and ask questions
- Clearly this would require significant more planning and organising, so Szara Coote offered to cover the admin and moderator role. Trevor to develop a role description and make a case for this to be a paid role.
- **Sarah Rae, Kevin James and Vicky Carr** expressed a keen interest in both the ADHD and Eating Disorders projects and this has been passed on to Nick Clarke
- The Impact of COVID on patient and public involvement will be carried onto next meeting agenda
- For the next meeting: Genomic Medicine Service Alliances - this is about building on the Genomes 100,000 project and understanding how genomics can identify patterns which will allow development of targeted treatment. PPI expertise that supports communication and engagement across the NHS GMS Alliance geography' will be required. It would be good if the Citizens' Senate could put up representation across the East? GMSA will have a critical role in facilitating strong collaborations across large geographies, working with patients and the public to build trust in genomics, and providing clinical leadership to enable the multi-professional workforce to use genomics safely, effectively and efficiently. The NHS Genomic Medicine Service Alliances will focus on reducing unwarranted variation and delivering the NHS Long Term Plan commitments to make demonstrable improvements to outcomes for our

patients and the populations. By taking this approach, the NHS will become the first health service in the world to systematically embed genomics into routine care and make significant strides to create a system focused on improving health, not just treating illness, able to predict accurately disease and tailor treatments, with shared decision making at its heart.