

Meeting report

Citizens' Senate meeting No 18

Cambridge Professional Development Centre, Foster Road, Trumpington

17th July 2018

14 people attended the meeting, we received apologies from 4 others. (holiday season, can't be helped). Thank you to all those who attended.

Discussion on future engagement (see notes issued with agenda)

I opened the session reflecting on why we volunteer to do this work. We are all living with long term conditions and have become experts by experience. We feel we have the knowledge and experience to inform & influence various health services and improve outcomes. Each of us are motivated and committed to being agents for change. We also agreed that it is our role to challenge public accountability. Our meetings are therefore designed to be informational and centred on supporting Patient, Carer & Public Involvement (PPI) Our partnership agreement which reflect the principles of the Coalition for Collaborative Care, was designed at the formation of the Citizens' Senate and remains the cornerstone of our involvement work.

The challenge

We have 22 members registered with the CS, yet only 13 on average attend the quarterly meetings. Our offer to work with partners in the East (EAHSN/NIHR/RDS) is dependent on as many active members as possible and who are available at meetings. Without this active involvement and a higher level of commitment, we cannot satisfy demand and it is difficult to allocate and plan resources.

We discussed the reasons for the limitations of members attending meetings and being available for involvement work. The majority want to maintain their membership of the Citizens' Senate but are already committed to other condition specific programmes and groups and cannot attend our meetings on a regular basis. After some debate, we agreed to create an associate membership for those who cannot attend more than two meetings a year. These members will receive all the information, guidance and speaker presentations, but will not be allocated involvement work.

In order to develop the membership consistent with our aims and aspirations, we have agreed to recruit more people to the CS. A number of events and presentations will be arranged to promote the CS and invite expressions of interest.

Action: Trevor to contact all those who haven't attended the last two meetings to ensure they are aware of new arrangements.

Action: Trevor to produce role spec for Associate Members

Action: Trevor and Mark G to develop suitable presentation to promote the CS (what's in it for us)

Action: Trevor to develop recruitment process and identify interested organisations i.e. Trust Patient Councils, CCGs, HealthWatch, local PPGs, and the patient groups associated with EoE Ambulance Service

Action: Trevor & Ann Nutt to work on information pack. Trevor will produce one pager fact sheet. We must market ourselves by showing the 'added value' and conveying 'what's in it for them'.

Peer Support in Medication Safety Project

I summarised our involvement and our application for Health Foundation funding (£30k) to pilot a study on peer support. This proposal is the continuation of the Citizens' Senate meds safety work we did last year and this. The pilot will evaluate the effectiveness of peer support in medication safety. In brief, our proposal is to train patients to have conversations with other patients to identify those who are not able to manage their medication effectively. Once an assessment is made, the patient is directed to the most appropriate service (pharmacy, GP, Nurse, community services) See link to the project - The title is 'Patient led peer support initiative to promote medication safety'

<https://q.health.org.uk/get-involved/q-exchange/browse-ideas/>

We were successful in first stage, quite unexpectedly we were shortlisted. From 130 applications, we made the shortlist of 25! If we are selected in the final (based on votes) award ceremony in Sept, it will be all hands to the pump and we hope some of you will be involved. More to follow...

Website progress

Tom Veal from Essiem Ltd, presented the next stage of our website development, following feedback from the working group. See attached screen shots. A key action for us is to ensure we have all our profile information uploaded. The home page content has already been produced and this has been signed-off. Outstanding information required are reports, training resources and an involvement register.

A key requirement was raised by Tony G. We must ensure we have a disclaimer on the website, in order to avoid liability. The disclaimer must ensure that any advice or guidance given, is based on our patient experience, with the understanding that everybody is different and each of us are responsible for our own decisions.

Action: Trevor to draft suitable statement

Involvement Register

One of the issues identified by the group is that we don't have visibility on who is doing what and the duration of their involvement. It is therefore difficult to know who is available for involvement work and scheduling work is not possible. Following discussion, I requested a volunteer to help with developing a system on our website, which could easily be updated as and when necessary. We need an online form that specifies the following:

- Host or originating organisation
- Type of involvement work e.g. Advisory Board, Steering Group, Project Team, Reviewer etc
- Duration of engagement
- Summary of objectives
- Benefits of our involvement
- Those who are available for engagement

Our current partnership for PPI are with:

Health Education England

Health Foundation

EAHSN programmes (AF related stroke/Suicide Prevention / Digital Hub)

STPs

NIHR

PPV for NHS England

In addition to above, many of us are involved with locality groups on an ongoing basis.

If anyone is available to make a contribution to the involvement register, please contact me.

Atrial Fibrillation Programme

Dr Amanda Buttery returned to give us an update of the AF programme. Her presentation highlighted the aims of the National AF Programme and the importance of identifying those with undiagnosed AF. The risk of stroke is ever present, unless steps are taken manage the condition. The EAHSN approach is to Detect, Protect and Perfect. Amanda explained the various devices and innovations available for GPs to detect AF. All CCGs in East of England were allocated Kardia devices for distribution to GP practices. Please check with your practice that they have received the devices and that they are registered and being used (not stored in a cupboard somewhere!!).

Action all - please approach your PPG to ensure your GP practice is using these devices

I have attached Amanda's presentation.

The next meeting is scheduled for Thurs 18th October 2018. Please book in your calendar.

END