

Sussex Carers Partnership

Summary of notes discussing the recommendations presented as part of the Sussex Carers Partnership Research Project Findings webinar held on March 24, 2021, 2:00PM - 4:00PM.

Financial Incentive...

This recommendation saw a debate about why an incentive was needed to help improve carer identification within healthcare services.

Feedback from carers as part of this research project highlighted how varied (and somewhat inconsistent) the approach was by some healthcare services in identifying and supporting carers, despite national [NHS good practice guidance](#) and [Quality Markers](#) for GPs.

Carers feedback as part of this research highlighted that without such guidance being mandatory and/or having the weight of a financial incentive, it was difficult to see how good practice would be implemented consistently for all carers pan Sussex.

A parallel comparison was also drawn to programmes for smoking cessation, which have been implemented in Primary Care Networks and have been linked with financial incentives.

‘...we also have the NHS 5 year plan...should be striving to get more quality markers for care in respect to good practice...’

- Mark Greening, Carers Commissioning Manager for West Sussex

Carers and the panel members felt that this recommendation should not be driven by simply asking GP practices to put carers on a list but having a robust follow on once a carer has been identified and registered.

‘ "Identifying" carers is one thing, but putting a name on a record, doesn't always result in better support/ information/ service...’

- Carer Comment from Webinar

‘ I agree with carer comments...it's not just about putting a carer on the list but looking at what does that mean and how will the carer be supported. What doors does that open for the carers?’

- Jane Lodge, Associate Director of Public Involvement for NHS Sussex Clinical Commissioning Groups

It was also suggested during the discussions that once a carer has been identified and registered with a GP practice they are offered a health check (for both physical and mental wellbeing), which could then link in with social prescribing services and onward support from carers' support organisations.

Carer Awareness Training and Term 'Carer'...

This recommendation saw a discussion around mandatory carer awareness training for healthcare staff, which would also tackle the use of the term 'carer'.

Healthcare services need to ensure they ask the question about being a carer in a nuanced way, rather than as a closed off question that only requires a Yes or No answer.

Plenary discussions highlighted that a wider diversity lens was needed in carer awareness training that highlighted the unique challenges for some of our diverse carer communities when accessing and navigating health services (i.e. ethnic minority, LGBTQ+ or Gypsy, Roma, and Travellers).

'...Everybody's experience will be different, but accessing and navigating services that maybe are not culturally appropriate, or are harder for parts of our communities...needs to also be considered...looking at the impact on people depending on their characteristics..'

- Samantha Allen, Chief Executive of Sussex Partnership NHS Foundation Trust

Plenary discussions also mentioned how the term 'carer' may be difficult for young carers (aged 18 and under) and their family to understand. It may be helpful in some circumstances to explain how the caring role impacts the carer rather than trying to explain a term that some will not identify with.

'It's difficult to have an agreed consensus on what term should be used, but I think 'carer' is the best that we have right now...what is important, and what we can do, is to make sure we are all very consistent in how we explain to people what the term means...'

- Tom Lambert, Chief Executive of The Carers Centre Brighton and Hove

During discussions, carers raised the issue that the term 'carer' was often confused with paid carer and this led to further discussion around the 'degrees of caring'.

'Could we (as a society) reach a point where the majority of individuals in the UK be termed a 'carer'? Most people have someone in their lives who they help/support to a greater or lesser extent. Would this then not 'water down' the role of carers living the 24/7 role?'

- Carer Comment from Webinar

Plenary members emphasised that assumptions should not be made and/or based on the hours a person spends caring and/or carrying out their caring responsibilities (i.e. intimate care and hygiene), but rather looking at the impact of the caring on each individual.

'...we need to be careful and not just to think about the amount of caring people do, but the impact on them and their lives as individuals...'

- Tamsin Peart, Strategic Commissioning Manager for Carers, East Sussex

Carers also echoed this:

'...I am now housebound with my husband 24 hours a day, and I have to tell you that this is different. I would be worried if we were now saying that the doctor has a list, and everybody is in the same situation...'

- Carer Comment from Webinar

Plenary members expressed the important of carers still being identified and registered even if they did not need carers' support services at point of sign up, but as a person's caring role and responsibility progresses, they are able to tap in and access support when needed.

'...important to know who is in a caring role even if they are not asking for support, but as their caring situation progresses and changes they may want more and more support...linked in with this is having an emergency backup...if we know who a carer is then we can see if there is a backup plan in place in case anything happens to them...'

- Steve Castellari, Engagement and Working Carers Lead, The Carers Centre Brighton and Hove

One carer also explained how important it was to encourage the person needing care and support to live as independently as possible to prepare them for a time when the carer is no longer around or unable to care. However, this carer did echo what we found in our research findings that some carers had experiences of being let down by some professionals and the weight of providing care once again fell upon the carer.

'...they [professionals supporting the person being cared for] are trying to make him more independent of me...but how can you trust other people when they let you down...who's door do you then knock at and who else is going to help...no wonder I am still doing this job [being a carer] at my age and when does it ever stop'.

- Carer Comment from Webinar

‘Contingency planning can be rather reactive when it needs to be proactive...what we want is at every point that either somebody is in a crisis situation or has a diagnosis, that you are saying to the person that comes in with them that this is going to have an impact on you and just recognising that this is going to change your life [as a carer] as well as the other person’s life [needing support]...’

- Gemma Scambler, Commissioning Manager at Brighton & Hove City Council

Carers and panel members’ comments also reiterated the importance of ensuring that if a carer is involved in the care and support of an individual/patient, health professionals must understand that the carer does not exist to mitigate the responsibility of health and social care services. Systems need to be in place to support and address the needs of the person being cared for so that the carer can focus on their own needs and wellbeing.

Clear and Consistent Communication...

The discussion around this recommendation centred on the need for clear and consistent communication as we heard from carers that communications from health care services were confusing and challenging.

‘...reflecting on communication...we, as professionals, make health and social care into a maze that carers have to learn to navigate and persevere with...and fight to get through...as we’ve heard today, carers are having to make multiple phone calls to get through to the right part of the system...and the jargon and the lingo that we as professionals use...makes communication challenging’.

- Jennifer Twist, Chief Executive of Care for the Carers (East Sussex)

Panel member Jane Lodge acknowledged that certain ‘lingo’ can be a barrier for carers in accessing services and the CCGs can certainly pledge help to ‘demystify’ the system for carers in a better way, which involves working with carers to come up with a solution. Carers in attendance offered to help and be a part of such a project.

A suggestion was also offered by panel members in utilising existing framework of engagement to help implement recommendations.

‘In West Sussex, we’ve looked at refreshing and changing our Joint Commitment to Carers, so that’s not just health and social care but also with the voluntary sector...that gives us a framework to use Sussex wide if needed [to implement and track the recommendations]. So, I am pleased to hear that we have a commitment from our health partners... [to work together to deliver this]’.

- Sonia Mangan, Chief Executive of Carers Support West Sussex

The Next Steps....

Carers thanked us for the presentation findings and for the opportunity to include and represent carers' voices. Panel members felt the final research report was 'essential in being used as a mandate for change'.

The CCG agreed and wanted to build on the momentum of the research findings and have extended the funding for this project. Therefore, the next step is to discuss with each of the three carers' support organisations the feasibility of implementing the suggested recommendations with carers in line with co-production principles.