

Sussex Partnership CCG Engagement Report Webinar

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The Carers Centre for Brighton and Hove
Care for the Carers (East Sussex)
Carers Support West Sussex

Steve Castellari, Jo Egan, and Adeelah Khan



Project Background

Inclusion Engagement Project commissioned by the Sussex Clinical Commissioning Groups (CCGs) and forms a part of their legal requirement to involve patients, carers and the public in their commissioning of health services.

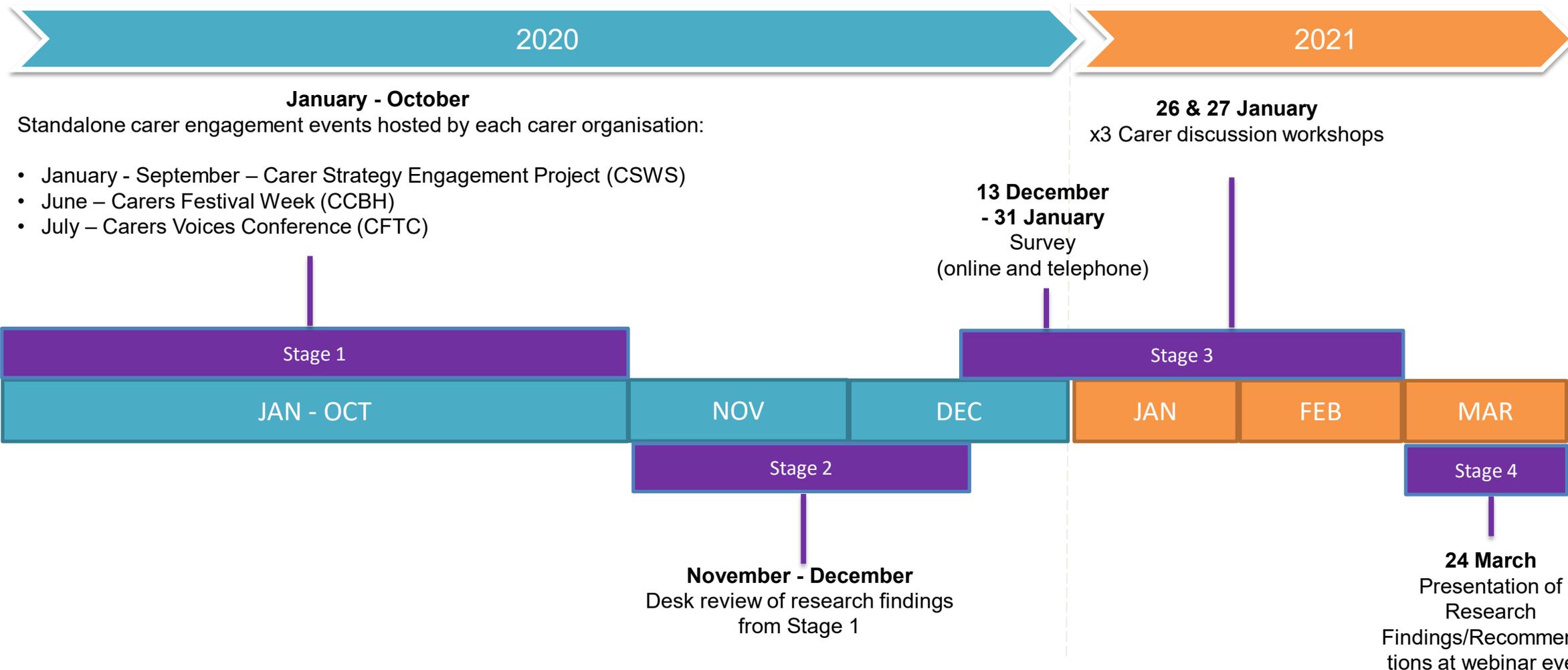
Research project delivered by the Sussex Carers Partnership, comprising of The Carers Centre for Brighton and Hove, Carers Support West Sussex, and Care for the Carers (East Sussex).

The three aims of the Inclusion Engagement Project were:

1. Seek the views of carers across Sussex regarding the challenges they have faced when accessing healthcare including being recognised as carers.
2. Establish if there are issues which may relate to a particular community or area of Sussex and differences compared to other areas and communities.
3. Identify the priorities for carers regarding healthcare services especially relating to Covid-19 and the vaccination program.



Research Stages 1 - 4



Stage 3 – Engagement

Three carer discussion workshops hosted in January 2021, each with a main theme of discussion:

- 1. Carers and Coronavirus: Planning for Recovery**
- 2. Caring Doesn't Come with a 'How To' Manual: Exploring Carer's Experiences of Navigating Healthcare Systems.**
- 3. The Invisible Army: Making carers visible**
 - Total of 22 carers participated in the workshops
 - Supplemented with survey covering same themes (online and telephone). Total of 118 respondents.



- **Difficulty Navigating Healthcare Services**
 - Need proactive approach from healthcare providers
 - Often a 'struggle' or a 'fight' to access care and support
- **Delayed/Cancelled Access to Healthcare Services**
 - Concerned by loss of regular checks and monitoring
- **Poor Carer Identification**
 - Carers not being recognised for their expertise
 - Feeling 'left out'
- **Term 'Carer' Not Understood**
 - Difficult to self-identify as 'carer' - term does not resonate or negates relationships

"[Person being cared-for] needs to have blood tests done at the GP practice, which is nearby, but reception said he couldn't. This has meant he's not had bloods done".

"...times when my role as a carer has been made difficult were when my father was in hospital. I often wasn't kept sufficiently informed, and often had to repeat myself to different doctors, nurses, specialists, but I think that this is symptomatic of poor communication, bad management (at high levels), and overworked staff that exists in hospitals."

"The way the carer question is phrased is so important. My gut reaction was no, I'm not a carer, I'm his mum! The question needs to be asked in such a way that it does not negate my primary identity as his mother. It needs to be a conversation to help me to understand that I'm a carer, and what doors that label might open for me, not just a tick box or a closed question. There needs to be sensitivity."

- **Concerns Around Carer Contingency**

- Lack of, or no, respite services during lockdown (i.e. day centres closed)

- **Impact on Carer Mental Health**

- 80% of respondents in workshops cited negative impact of caring on mental health
- Includes loneliness and isolation and feeling invisible and anxious

- **Confusing Messaging About Covid-19**

- Lack of consideration for carers who are also clinically vulnerable and carry out a caring role

- **Inconsistent Communication**

- Communication between carers and healthcare providers seen as inconsistent
- Good communication dependent on individual/professional rather than a standard applied to all

"I'm finding that I feel more invisible now than I did last year.... there is a degree of feeling more isolated and, oddly, lonely on occasion, even though my wife is next door with her PA."

"When my partner goes to health appointments, I've not been allowed in to accompany him - which means we're missing out on key information as my partner can't remember or understand the information the health people have given him....it's so frustrating to be left out."

"...little consideration given to carers who are also in the "clinically extremely vulnerable" category! The assumption is always that they (the vulnerable person) are the "cared for" rather than the carer themselves! Letters are sent out saying stay at home, don't go food shopping, avoid chemists etc. but what if you are supposed to be caring for someone who couldn't cope/survive without the carer doing those things?"

Recommendations

1. Incentives to Identify Carers

- Financial incentives for health services to identify carers
- Robust inclusion and engagement with Patient Participation Groups (via GP Practices)

2. Introduction of Mandatory Carer Awareness

- Mandatory carer awareness training for all healthcare staff
- Blended approach comprising of e-learning and face-to-face delivery

3. Centralised Carer Records

- Medical records with field for 'carer' prominent ('unknown' should not be an option)

4. Reduce Negative Impact of Caring on Mental Health

- Commissioning of resilience-building training for carers
- Mandatory mental health training for all healthcare staff

5. Regular and Consistent Messaging

- Utilise trusted sources (NHS, GP, Government) to cascade information to carers identified about annual vaccination programmes

6. Road Map for Services and Support

- Clear, concise and accessible recourse mapping out the services and support available.