

Carers Co-Production Project – You Said, We Did Report

Introduction

The Norfolk and Waveney Integrated Care Board approached Carers Voice Norfolk and Waveney and Caring Together to deliver a Carers Co-Production Project that focused on:

1. Co-producing a Carers Identity Passport
2. Carer awareness-raising for health and social care professionals.

Both organisations were committed to ensuring Carers voices and experiences were at the heart of the work that they did on this project. This summary report sets out what Carers told us during this project and what we did as a result.

How were Carers' voices heard?

A priority was to ensure that the co-production involved all ages of Carers, in different situations, particularly making sure we heard from Parent Carers, Young Carers and Young Adult Carers. We did this by providing a variety of ways for Carers to get involved:

- In February 2022 Carers Voice hosted an online workshop to hear whether Carers wanted a Carers Passport and if so what it might look like. It was attended by over 100 Carers and professionals.
- Anyone unable to attend was encouraged to contact Carers Voice to ensure their views were heard
- Information from the workshop was sent to those who could not attend
- Following the workshop, a Co-production Steering Group was established for this project with strong representation from Carers as equal partners, including Parent Carers and a Young Adult Carer. Other members of the group were from the Integrated Care Board, the three acute hospitals (Norfolk and Norwich University Hospitals NHS Foundation Trust, Queen Elizabeth Hospital King's Lynn NHS Foundation Trust, James Paget University Hospitals NHS Foundation Trust), Norfolk Community Health and Care Trust, East Coast Community Healthcare and Norfolk and Suffolk Foundation Trust.
- We held focus groups to capture the experiences of Carers in relation to health settings. Carers had the opportunity to review the Carer awareness materials, make suggested changes and provide content to use in sessions (e.g. voice notes, case studies, videos). There were online and in-person options for this.

- Carers worked with Norfolk County Council to produce videos to be used as training materials around the discharge process and the importance of being identified as a Carer at an early stage through the development of the Carers Passport.
- These discharge videos were shared and live streamed at the launch of the Integrated Care Board on July 1st 2022.
- We produced a paper for the Integrated Care Board which contained the key messages from Carers of all ages and featured a variety of case studies. Carers were part of producing this report.
- Carers requested that the Carers Passport was launched on Carers Rights Day on November 24th 2022
- The launch of the Carers Passport had just under 100 attendees and questions from Carers were welcomed.
- Carers from the Co-production Steering Group spoke at the launch and produced 4 videos on the development of the passport, their experience of co-production, how the passport can be used and developments for the future. The meeting was live streamed and recorded.

You said, we did...

This is a summary of what carers (including Young Carers and Parent Carers) have told us during this project, and what we collectively have done (or are doing) as a result

You said...	We did....
<ul style="list-style-type: none"> - That you wish to be identified as a Carer at as early a stage as possible so that you are valued, respected, listened to and involved in the health and care pathway of the person you care for. 	<ul style="list-style-type: none"> - Carers Voice planned and held an online virtual workshop in February 2022 for Carers to establish whether Carers wanted a passport and what it might look like - Carers Voice led on the co-production (with Carers and healthcare practitioners) of a Carers Identity Passport which would be recognised in healthcare settings. - A Co-production Steering Group was established for this project with strong representation from Carers as equal partners, including Parent Carers and a Young Adult Carer. - The steering group planned and delivered a Virtual Carers Conference in Carers Week 2022. The topics were suggested and agreed by Carers and the sessions were attended by 100 Carers and professionals. The views and experiences of Carers were embedded into the content of the presentations and Carers also contributed in real-time through the chat and the discussion section.
<ul style="list-style-type: none"> - That you wanted consistent recognition and continuity across all health and community care settings 	<ul style="list-style-type: none"> - The Carers Identity Passport is recognised across the three acute hospitals (Norfolk and Norwich University Hospitals NHS Foundation Trust, Queen Elizabeth Hospital King's Lynn NHS Foundation Trust, James Paget University Hospitals NHS Foundation Trust), Norfolk Community Health and Care Trust, East Coast Community Healthcare, and Norfolk and Suffolk foundation Trust. - There are plans for the passport to be recognised across primary care as well.

<ul style="list-style-type: none"> - That you were having negative experiences of hospital discharge: - There was a lack of communication and Carers didn't know who they should talk to - There were delays in discharge processes - Hospitals weren't considering the views of the Carer 	<ul style="list-style-type: none"> - We supported Carers to feature in short videos around hospital discharge to raise awareness of the challenges they face, and the importance of their role. These videos were shared at the launch of the Integrated Care Board and will be used as training materials - Carers Voice undertook to create a Discharge Task and Finish Group which meets on January 30th 2023. Carers Voice continue to work with Healthwatch Norfolk, the Integrated Discharge Director, the Directors of Nursing, the Patient Experience teams from the hospitals and social care improving identification, involvement and support for Carers in relation to hospital discharge. - Caring Together have delivered Carer awareness training to discharge coordinators at the Norfolk and Norwich University Hospital and will be looking to replicate this across the hospitals - Carers Voice have produced a staff briefing around the Carers Passport so that this can be shared with discharge coordinators.
<ul style="list-style-type: none"> - That Carer awareness materials didn't cover enough about Parent Carers 	<ul style="list-style-type: none"> - Parent Carers have provided case studies in relation to their experiences and the issues they face to be used in training. - Quotes from Parent Carers from Caring Together's Carers Speak Out report will also be added to training - Statistics are now available from the Norfolk Parent Carer survey that can also be used in the training
<p>You said...</p>	<p>We did...</p>
<ul style="list-style-type: none"> - You wanted health and social care professionals to be more aware of Carers and the important role that they play - You wanted a Carers Lead on the Integrated Care Board to advocate for Carers 	<ul style="list-style-type: none"> - Caring Together organised two in-person roundtable events with the new Chief Executive Officer of the Integrated Care System, Tracey Bleakley. One was for adult Carers, Parent Carers, Young Adult Carers and Carer support organisations, and the other was specifically for Young Carers. - Carers Voice created a staff briefing document to ensure staff are aware of the Carers Identity Passport and Carers are recognised. - Caring Together and Carers Voice worked with the steering group to produce a paper that went to the Integrated Care Board and to the hospitals and health settings involved in the project. This paper gave various examples of how caring affects the health and wellbeing of Carers and highlighted the experiences of local Carers. The paper also contained a series of recommendations for the Integrated Care Board. - The Chair of the Integrated Care Board supported and spoke at the launch of the Carers Identity Passport.

	<ul style="list-style-type: none"> - A new executive lead for Carers has been appointed for the Integrated Care System (ICS). The new lead who is Director of Nursing and Quality at Norfolk Community Health and Care attended and spoke at the launch of the Carers Identity Passport and is chairing the Discharge Task and Finish Group.
<ul style="list-style-type: none"> - That for any Carers Passport, it should be administered by a single point of contact 	<ul style="list-style-type: none"> - Carers Voice are the single point of contact for the distribution of Carers Identity Passports - Single point of contact for monitoring and evaluation
<ul style="list-style-type: none"> - There needed to be options for Carers who were not able to access information or participate online, but also a digital option 	<ul style="list-style-type: none"> - The Carers Identity Passport is available from Carers Voice both as a hard copy and digitally. - There is a QR code that can be scanned to access the form to request a Carers Identity Passport. - There is a telephone number for help to receive a Carers Identity Passport.
<ul style="list-style-type: none"> - The Carers Identity Passport needs to be accompanied by a lanyard. Carers also requested the name 'Carers Identity Passport,' the information on the card including issue date, the visual appearance of the card and supporting promotional materials. 	<ul style="list-style-type: none"> - These factors have all being incorporated as part of the project and development of the Carers Identity Passport by Carers Voice. - Carers requested an issue date instead of an expiry date due to the longevity of most caring roles.
<ul style="list-style-type: none"> - Carers wanted to be able to access the Carers Identity Passport before entering a healthcare setting 	<ul style="list-style-type: none"> - The Carers Identity Passport can be requested from Carers Voice online or via telephone at any point - Carers Voice has created a leaflet which has been shared via social media. - Carers Voice produced a press release about the Carers Identity Passport. This was shared with local media outlets. - Carers Voice Chief Officer and Carer interviewed by BBC Radio Norfolk about the launch of the Carers Identity Passport and how Carers can register.

The Carers Identity Passport can be requested by visiting www.carersvoice.org/carers-identity-passport

