# TRAVERSE

# System Pressures in Sussex

Deliberative engagement findings

**Sussex Health and Care Partnership**

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# Contents

# Foreword

The COVID-19 Pandemic has been a time when the strength, creativity and commitment of the NHS, public sector staff, the voluntary and community sector and volunteers has shone through. However, it has also meant that the NHS and Social Care services have faced unprecedented pressure, which has undoubtedly had a profound impact in a range of ways: on our workforce within services, and those working to maintain care; on patients, and family and friend carers; and on voluntary and community sector organisations who have been supporting the most vulnerable people in our communities. National news stories have highlighted these pressures and the impact, often in a very stark and emotive manner. In the earlier stages of the pandemic, the "Clap for Carers" movement was a demonstration of public feeling and support.

As levels of infection have receded and resurged over the past two years, the impact of COVID-19 on workforce capacity and on demand for services has continued to be felt and has been exacerbated by seasonal pressures on health and care services.

Sussex Health and Care Partnership's constituent organisations (NHS organisations and Local Authorities) have communicated with our population throughout this period and have changed messaging according to the level of pressure and the need for people to access and receive care in different ways. In addition, there have been changes in how services are delivered, and innovative ways of working that have been put in place to try to mitigate these pressures and how they impact on people in need of health and care services. However, we are aware that different ways of working were established at pace and now, as we return to a new normal, we are reflecting on how to build on reflections from the pandemic to meet the needs of our population better.

The deliberative engagement process provided an opportunity to form a dialogue with a range of people from our local communities about the impact of COVID-19 on health and care services, and to include a diverse range of voices and perspectives in exploring some of the challenges we have been considering as a system throughout this pandemic. The expert facilitation from Traverse created a safe and supporting environment for this discussion and enabled a range of people to be honest and open, and to share their views and experiences. It has helped us think both how we communicate with people and has also provided some practical suggestions for support, both of which have been invaluable.

We would like to thank all those who took part, sharing their views so honestly and with such respect and appreciation for the work that health and care services continue to do. We will ensure that we continue the dialogue we started here, in the first instance by letting people know how key takeaways and suggestions detailed in this report have shaped our work.

**Amy Galea**

**Executive Director of Primary Care**
**Sussex NHS Commissioners**

# Executive summary

## Background

Pressures on the health and care system in Sussex, and around the UK, have been mounting throughout the COVID-19 pandemic. Alongside rising demand for health and care services, the capacity of services has been reduced due to the impact of staff illness and isolation, and other system and service changes in response to the pandemic. As a result, the relationship between people and the NHS has also been put under pressure.

Sussex Health and Care Partnership (SHCP)commissioned **Traverse** to design and facilitate a deliberative engagement programme, which would support a dialogue between Sussex residents, senior leaders from the Integrated Care System (ICS) and other key stakeholders. The aim of the programme was to support discussions around these challenges, and explore the role of individuals, communities, and service providers in reducing pressures on the health and care system.

## Programme design

The programme had three phases: learning, discussion, and deliberation.

- **Phase 1, Learning:** The first phase involved all 47 participants as they attended an information session hosted by senior leaders from the Integrated Care System (ICS). This information session provided participants with an overview of the pressures facing the health and care system in Sussex, and how they interrelate.

- **Phase 2, Discussion:** For the second phase, participants took part in a small discussion group to reflect on what they had learned and further develop their views. These groups included: two mixed groups of Sussex residents; a group of young people; a group of people from minority ethnic backgrounds; a group of carers; a group of representatives from Healthwatch and Voluntary and Community Sector (VCS) organisations, and one group of local councillors and Community Ambassadors.

- **Phase 3, Deliberation:** Finally, a sub-set of participants from each of these groups (16 people in total) took part in a deliberative workshop involving leaders from across the ICS. The online workshop allowed participants and system leaders to build on previous discussions, and to generate ideas and explore opportunities to support individuals and communities to navigate health and care services responsibly and effectively.

## Findings

### Open and honest communication with the public

Participants felt that more **open and honest communication** between the NHS and members of the public would help to build understanding and trust, and reassure

people when there were delays. When services were strained, participants wanted more information about why decisions were being made and what people can do to help. There was frustration articulated by some participants about the lack of consistency in whether people can get access to the information they need. Participants highlighted the role of regular updates to reassure people that they hadn't fallen between the cracks.

## Getting the right information to the right people

Participants felt more could be done to **ensure that information made it to those who need it most**. Participants felt there was an overreliance on social media to disseminate information about system pressures and service changes. They felt that physical forms of information distribution, such as leaflet drops, remain valuable, particularly for reaching digitally excluded people. Participants saw an opportunity to communicate clearly around the different ways of accessing information and support. They felt this information should be made available in community settings to help to reach people before they have decided to go to A&E or the GP. Some participants felt that schools and colleges could play an important role in informing young people about how to navigate and access health and care services responsibly and effectively.

## Building bridges across the health and care system

Participants also wanted to see **better connections across the health and care system**, to help prevent people from falling between the cracks. By strengthening communication between services and giving patients greater access to their own records, participants felt people could take better control over their own health and care. Participants felt that voluntary and community sector organisations could also play a role here, connecting lived experience and community networks to services such as PALS and care coordinators. Participants highlighted that without these support systems, there would be too much of a burden on family members and carers.

# Next steps

As the health and care system continues to respond and adapt to changing pressures, the findings from this programme can feed into ongoing planning activities, beginning with a Routes to Action meeting with wider health and care service leaders in early February 2022.

Supporting ongoing discussions with people and communities is a priority for the ICS, and Sussex Health and Care Partnership's Public Engagement team will ensure there is an opportunity for those who have participated in this deliberative programme to come together later in 2022, to hear about progress and opportunities to stay involved.

# 1. Introduction

## 1.1 Background

Pressures on the health and care system in Sussex, and around the UK, have been mounting throughout the COVID-19 pandemic. Alongside rising demand for health and care services, the capacity of services has been reduced due to the impact of staff illness and isolation, and other system and service changes in response to the pandemic. As a result, the relationship between people and the NHS has also been put under pressure.

Sussex Health and Care Partnership wanted to have an open conversation with Sussex residents and stakeholders, to discuss these challenges and reach a collective understanding of the situation, and what role individuals, communities, and services have at a time of unprecedented pressure. To support a diverse group of residents and stakeholders to take part in this conversation, Traverse[1] was commissioned to design and facilitate a deliberative engagement programme exploring people's attitudes and ideas around the pressures facing the health and care system.

Deliberative engagement methodologies are used by a range of organisations and institutions to support people to deliberate on topics that impact their lives, so that decision-making is informed by people's concerns and priorities. In "Twelve Key Findings in Deliberative Democracy Research"[2], Curato et al note that deliberative processes can mitigate group polarisation, embrace pluralism rather than forcing contrived consensus, and support the involvement of traditionally marginalised groups. The distinguishing characteristics of deliberative engagement, and the ways in which they manifested in this programme are described in the table below.

| Characteristic | How this was reflected in our approach |
|---|---|
| 1) A learning experience concerned with evidence | Providing balanced information on a topic to participants, introducing them to specialists to talk through the topic and answer their questions. |
| 2) Long-form and reflective | Usually held over several hours, and sessions (not just a one-off workshop). |
| 3) Involves a diversity of voices | People from a range of backgrounds are specifically invited to participate. |
| 4) Embraces complexity while exploring consensus | Searching for the "why" behind views, problematising the topic, exploring areas of agreement and disagreement. |

Figure 1, Distinguishing Characteristics of Deliberative Engagement

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[1] https://traverse.ltd/
[2] https://www.amacad.org/publication/twelve-key-findings-deliberative-democracy-research

## 1.2 Programme objectives and design

The deliberative engagement programme was designed to:

1. Explore people's different **experiences, priorities, and ideas** in relation to the pressures affecting the health and care system and reach a **collective understanding** of the situation.
2. Support **open and honest** conversations between members of the public, stakeholders, and system leaders about how we can address these challenges.
3. Identify opportunities **to build and maintain public confidence and trust** in the health and care system, and to support **ongoing, open, and honest conversations** with the public about action to address system pressures.

We recruited 47 people to take part, across seven small groups. There were five "public" groups, and two "stakeholder" groups. The public groups consisted of two mixed groups of Sussex residents with a range of backgrounds and experiences; a group of young people; a group of people from minority ethnic backgrounds; and a group of family and friend carers. The stakeholder groups involved one group of representatives from Healthwatch and Voluntary and Community Sector (VCS) organisations, and one group of local councillors and Sussex Health and Care Partnership Community Ambassadors. See Appendix A for a summary of participants and how they were recruited.

The programme had three phases: learning, discussion, and deliberation. The full group of 47 participants took part in the first two phases of the programme, where they learned about the pressures facing the health and care system, and then explored their views in relation to these challenges. To transform this conversation into one which could generate ideas for ways to move forward together, a subset of participants from across the seven groups (16 participants in total) then attended the final, deliberative workshop. See Appendix B for a summary of activities in each phase, and Appendix C for a summary of how ICS leaders were involved in the programme.
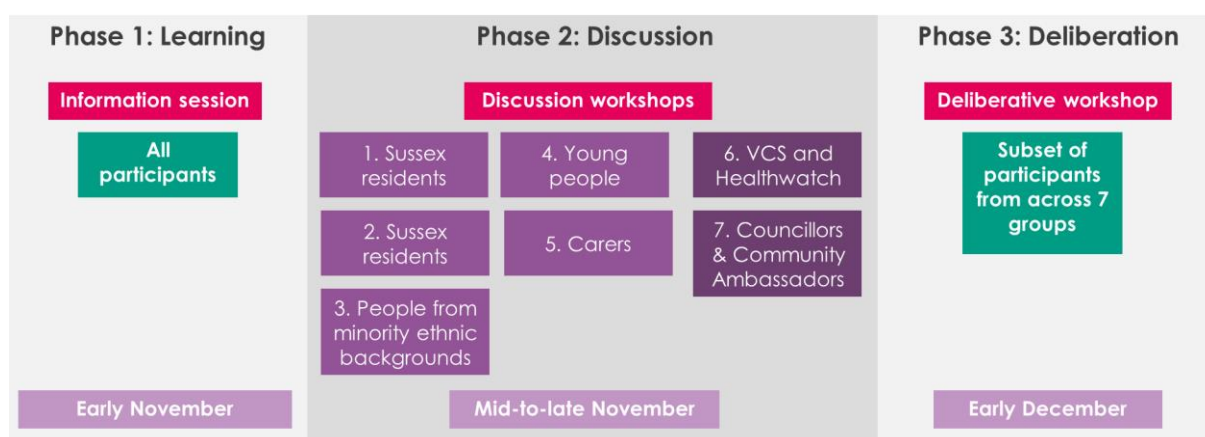


Figure 2, Programme design

## Phase 1: Learning

In the first phase of the programme, participants attended one of two online introductory sessions where they heard from the following senior leaders from Sussex Health and Care Partnership about the pressures facing the health and care system:

- Maggie Keating, Urgent and Emergency Care Programme Director
- Amy Galea, Executive Director for Primary Care
- Tom Gurney, Executive Director of Communications and Engagement
- Kerry Lloyd, Deputy Chief Nursing Officer

This gave participants the opportunity to understand the context behind the project and why now was the right time to have these conversations. It also allowed participants to ask questions and seek clarification on the pressures faced by health and care services. A Q&A was facilitated to provide space for participants to engage directly with ICS leaders.

## Phase 2: Discussion

In the second phase of the programme, each group took part in a facilitated, online group discussion, where they explored their own feelings, perspectives, and ideas in relation the system pressures they had learned about. Discussions were centred around understanding participants' reaction to and understanding of system pressures; exploring views in relation to trust between residents and the NHS; and sharing perspectives and ideas in relation to where the responsibility lay for addressing system pressures.

## Phase 3: Deliberation

In the third phase of the programme, a subset of participants from each group attended a final, deliberative workshop. They were selected based on availability and interest, with some preference given to ensuring a diverse group of participants. A full breakdown of the attendees can be found as part of Appendix A. The deliberative workshop was an online, half-day workshop, co-delivered by Traverse facilitators and the following ICS leaders.

- Maggie Keating, Urgent and Emergency Care Programme Director
- Amy Galea, Executive Director for Primary Care
- Jane Lodge, Associate Director of Public Involvement and Community Partnerships
- Dr Claire Woolcock, Medical Director – Mental Health, Transformation

The workshop was split into three parts:

- First, participants reflected on the process so far. This included key themes and insights taken across the discussion workshops.
- Through a carousel activity, participants then explored three key opportunity areas with ICS leaders. The ICS leader were able to field questions and provide expert insight into each topic area participants explored.

- Finally, participants surfaced what they saw as key priority actions to address some of the challenges explored through the workshop.

## 1.3  Interpreting the findings

### Analysis Approach

The audio from discussion workshops in Phase 2 was recorded and transcribed. A thematic analysis of these notes supported the framing of the final, deliberative workshop – highlighting the key opportunity areas surfaced by participants across the seven groups. The audio from the deliberative workshop in Phase 3 was also recorded. These notes were reviewed and coded thematically.

### How to read the report

In this report, we use non-specific quantifiers to give a sense of the weight of sentiment in participants' views, as follows [3]

- 'Most' or 'majority' when a clear majority of participants shared a similar view
- 'Some' when a minority of participants shared a similar view
- 'A few' when a small number of participants shared a similar view

Where there are many different views on an issue, more prominent views are generally reported first. We use terms such as 'consistent', 'commonly held', or 'less common', to show the relative frequency of occurrence of views.

It is also important to note that, like most qualitative research studies, this data is not generalisable to the wider population due to the small sample size.

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[3] It is common practice to use this approach when reporting qualitative data, instead of reporting numbers or percentages of participants, because numeric quantifiers would be misleading given the small sample size.

# 2. Open and honest communication with the public

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**Key takeaways**

Participants appreciated the opportunity to learn about the pressures facing the health and care system in Sussex and felt that more **open and honest communication** between the NHS and members of the public would help to build understanding and trust, and reassure people when there were delays.

- Participants wanted residents to have more information about:
  - The **status of different services** – where pressure is coming from, what is being done to address it, what changes to expect and how long they will be in place.
  - **What people can do to help**, and **how to use services responsibly**.
- When system pressures lead to service changes, or changes and cancellations to people's appointments, participants wanted to have **more information about why these decisions are being taken**.
- Participants were frustrated by the lack of consistency in how and whether people were able to get the information and support they need (across different areas of Sussex) and wanted to see a **commitment to addressing these disparities**.
- Some participants felt that **more frequent reminders and updates** around appointments would help people to feel more supported and connected. Whether via text, email or post, participants saw ongoing communication as an important way of **reassuring people that they hadn't fallen between the cracks**.

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## 2.1 Informing people to build respect and understanding

In response to learning about system challenges in the information session, participants saw an opportunity for more open and honest communication with the public about the challenges the NHS is facing; the reasons for system changes; and the opportunities and challenges any changes could bring. These participants felt that communicating this information to the public could help residents to become more empathetic and understanding of the pressure NHS staff are under and of delays and other service changes.

*"More than ever before, care staff and health staff are seen as heroic and long may that continue." - VCS and Healthwatch discussion group*

Most participants in the information and discussion workshops reported finding it interesting to learn more about how the health system worked, and to hear insight directly from professionals, rather than in the news or through an institutional social media account. These participants felt that other residents would benefit from a similar experience. One participating community ambassador noted that most people he talks to have a limited understanding of the structure or scope of their local health and care services. This participant suggested providing the public with an accessible overview of their local health and care system and how it interacts with, or is supplemented by, local voluntary and community organisations to help people understand how the system can support those that need it. Most participants agreed that Sussex Health and Care Partnership could do more to inform the public about the care and support that is available. This suggestion was echoed in the young people's discussion group.

*"I feel like communication with the public would help with trust. Making people aware of the difficulties and setting out a plan of how they'll address issues, for example a website on how they're improving services in the local area."*- Young people's discussion group

However, some participants said that awareness about system pressures made them feel reluctant to access services, as they felt they could be taking an appointment away from someone that might need it more. These participants felt worried that they might not be able to access the care they need, and hearing about system pressures exacerbated this feeling. This left these participants feeling unsupported. However, a few other participants felt that this was a positive change, as it resulted in those participants using alternative options, such as getting advice in the pharmacy.

*"I'm so aware of the pressures the staff are under, I'm desperate to try to prevent further loads going to them, and it's made me reluctant to seek services where I can kind of get by... It's kind of a moral dilemma when you do need something, and you have to weigh up: is it worth bothering them? It's not a bad thing as such, but it's a change for a lot of people who would call straight away and that's a cultural shift that will take a while to develop."* - Carers' discussion group

## 2.2 Ongoing communication to ensure people feel supported

In addition to open communication about the challenges facing a specific service along with planned changes, participants felt that more regular communication with individual residents could play a role in reassuring people and building trust and understanding.

*"[…] the more we communicate, the more we feel that we have been supported."* – Deliberative workshop

Some participants shared their own experiences, which included waiting a long time for a referral appointment, only for it to be cancelled without explanation, and waiting for long periods of time for an appointment or referral without regular updates.

*"[…] quite often these emails were going missing, or you wouldn't get*

*replies for 2-3 weeks… and you'd try to chase it up, it's all come about because of the pandemic. I appreciate the problems, but it doesn't help and adds to the frustration when you don't actually know what's happening."* - Sussex residents discussion group

Some participants also expressed feeling frustrated by disparities in accessing care within Sussex. For example, people registered at one GP surgery might experience these issues, while someone registered at somewhere else might not. Similarly, some participants noted that different areas use different technologies or services for patient communication, and a few participants felt unsure about which options were available for their own use.

A few participants shared positive experiences of communicating directly with health and care services. For example, one participant spoke about how comforting they found text message reminders about appointments. This participant reported feeling that these small reminders relieved some of the pressure associated with health management, particularly as a carer. Another participant spoke about how much they would appreciate regular updates while waiting for a referral, as it would provide reassurance. Most participants in the deliberative workshop recognised the value of regular patient communication in helping people to feel informed and reassured.

*"Going into different ways of communicating, making it more normal and personal so people get a sense of being cared for. The example of getting a text made you realise you are a human being in this big complicated system and that someone is looking out for you. It's important that people know that they matter."* – Deliberative Workshop

# 3. Getting the right information to the right people

## Key takeaways

In addition to exploring the kinds of information that would support people to better understand system pressures and how to navigate health and care services, participants reflected on the best ways of **getting this information to the people who need it**.

- Participants felt there was an **overreliance on social media** to disseminate information about system pressures and service changes. They felt that there should be a range of approaches to getting the right information to the right people.

- Participants saw an opportunity for **websites with important information** (including the Sussex Health and Care Partnership website and individual GP surgeries' websites) to be more accessible (particularly for those accessing websites using a phone) and provide easier access to important information. They suggested **involving patients, carers and families in updating and simplifying online content**.

- Participants felt that **most people use Google to find information about health and care services**, and highlighted an opportunity to improve the way the right messages can be promoted in Google search results.

- Participants felt that **physical forms of information distribution**, such as leaflet drops, remain valuable, particularly for reaching digitally excluded people.

- Participants highlighted an opportunity to **distribute information about different ways of accessing information and support in community settings**, to help to reach more people, and to reach people sooner – before they have decided to go to A&E or the GP.

- Participants felt there should be **more forums to have two-way conversations** between residents and NHS staff.

- Participants saw a **role for schools and colleges** to teach young people about the health and care system. Young people taking part in the process highlighted **the PHSE curriculum** as one space to support young people to develop their understanding of health and care system.

- Participants saw a **role for young people then being able to share this knowledge and support people in their family and wider community** to understand and navigate health and care services more effectively.

## 3.1 Effective use of social media and online communications

When reflecting on different ways of sharing information with people across Sussex, most participants in the deliberative sessions were critical of the use of social media. Some participants felt that relying on social media excluded people that could not, or choose not to, use social media. Some participants talked about digital exclusion, and a few participants highlighted that they wouldn't know how to use social media themselves.

> *"If that was me, I wouldn't even know how to use that. So, if I went on a website that said, 'there's more information on the Instagram account', that would be useless to me."* – Deliberative workshop

Some participants struggled to recollect seeing any information about health, or health and care services, on social media. Only one participant felt they remembered seeing an advert promoting the COVID vaccine. Some of these participants talked about the value of targeted adverts placed on social media and speculated that perhaps they hadn't been in the targeted demographics. A few participants suggested that incorrect assumptions about the reach of social media often drove its use.

In addition, some participants felt that social media was an inappropriate platform for health information. A few of these participants noted that they wouldn't consider using social media to search for health information, in part because it was difficult to accurately search for information on social media platforms. A few participants noted that most people use social media only for its intended purpose, to keep in touch with friends. Notably, the young people participating in the deliberative session agreed with this sentiment, too.

> *"I mentioned that social media has its place, but we need to get out of the idea that everyone is on social media. I'm not, my wife isn't, my friends aren't."* – Deliberative Workshop

On the other hand, a few participants felt that social media had a place in effective communication about healthcare. A few participants noted that it was useful to use social media as an additional point of contact, which provides information in a different format or can direct people to further information.

> *"I wouldn't go immediately to social media because it can be difficult to search for specific things. I would probably Google it, that's the first thing I would do."* – Deliberative Workshop

When trying to access information about care online, most participants in the deliberative workshop felt that they would use a search engine or use the Sussex Health and Care Partnership (SHCP) and other NHS websites, such as GP surgery pages. These participants noted that it was often difficult to find the information they wanted, or to know if the information they had found was correct. While participants valued the scope and ambition of the website, a few of these participants felt that

some of these websites were difficult to navigate. A few participants also mentioned accessibility issues, including these websites not displaying correctly when viewed on a mobile device. Participants felt that this could prevent people, particularly younger people, from getting the information they need.

## 3.2 Hard copy and face-to-face communication

Most participants saw an opportunity for greater and more effective use of more traditional communication methods, including distributing hard copy information (leaflets, posters, information cards), and sharing information through events and other types of face-to-face communication.

During the conversations about communication in the deliberative session, a few participants spoke positively about 111 and the way that scheme was promoted. One participant highlighted the effectiveness of the 111 business-card scheme to highlight the potential value of offline, physical information distribution.

Similarly, some participants in the deliberative workshops felt that leaflet drops could be an effective way of communicating with the public about the different, and most appropriate, ways to access the care they need. A few participants also suggested that physical information could be sent to people following an appointment, or alongside letters to patients – "piggybacking" on existing communication channels. A few participants also felt that physical information presented in different languages could better support people that speak English as a second language.

Some participants noted that there was often a range of information available inside GPs or other primary care access points, but that it was often too late to provide helpful information at that point – people in a waiting room have already potentially missed alternative ways of getting support and information. These participants spoke about how important information distribution before the point of access can be for preventative care, particularly around mental health.

Participants provided some examples of community communication points that could be used for information distribution, which included:

- community magazines, such as *Eastbourne and out*.
- town halls, libraries, and other community spaces.
- community groups.
- religious groups and places of worship.
- schools, colleges and youth work organisations.

Participants felt that leaflets or adverts could be placed in these locations to help people to learn about how to access their local health and care system. These participants emphasised that this approach could also help to reach people who aren't currently in contact with health and care services, or who might be digitally excluded. In particular, one participant talked about how information distribution at places of worship could help elderly people from minority ethnic and religious groups

to access the care they need.

*"If you want to find out how people feel, get into the community – that's what's missing and if they want to bridge the gap, they need more open communication from a non-judgemental point of view."* - Carers' discussion group

Participants also felt that one-way communication (through leaflets or posters) could only go so far, and that some of this information is better communicated through conversations where people can share their concerns and questions. Participants felt that more forums for the residents and people working in the NHS to come together would be hugely beneficial.

*"I don't think we've looked hard enough at how we communicate. There's also something about not just communicating or signposting… but talking to people and getting people into other environments so they can see it, and feel it, and learn it."* – Deliberative workshop

During the deliberative workshop, young people highlighted the potential for schools and colleges to support better understanding of the health and care system amongst young people. They felt this would help young people to navigate the health and care system more effectively, as well as sharing this information with their families and wider networks.

*"Offering like a little teaching package is every teacher's dream. Resources, assessment material, PowerPoints, some posters. It's very helpful. In schools some kids can become ambassadors for things, it's really good ownership. Approaching schools, suggesting it would be good for the [PSHE] curriculum."* - Deliberative workshop

Some participants felt that personal, social, health and economic (PSHE) education lessons could focus more on teaching young people about their local health and care system and how to access the services it offers. A few participants noted that schools and colleges are placing more emphasis on the pastoral support offered to students, and felt that the health and care system could help to inform and shape the support that's being provided. One of the young people in the deliberative workshop noted that they would turn to their college for advice and support before trying to access information online.

Participants in both the young people's discussion workshop and the deliberative session also talked extensively about mental health support for young people and the challenges that they face. These participants highlighted the importance of ensuring that young people are aware of the services that are available to them, to ensure that they know how to access support if they need to.

*"Mental health conditions that affect a lot of people but might be overlooked if not everyone knows about the symptoms and about how to access services. I'm lucky because I have good relationship with my parents who helped me through that, but not everyone has that and*

*might not know how to access that."*- Young people's discussion group

In addition, a few participants highlighted that recent service changes have enabled young people to have more control over their own health, including booking their own appointments, and this could lead to young people needing more support. A few participants noted that young people might rely on the capacity and ability of their parents to access care, and that ensuring young people are supported through school helps to address inequality.

In addition to supporting young people to access care, most participants in the deliberative workshop spoke about the potential role that well-informed young people could have in supporting other people. In particular, these participants spoke about the importance of family connections, and how young people could support older or digitally excluded family members to access and navigate their care. Some of these participants also highlighted that encouraging young people to take up this role in their families could help to mitigate the impact of service changes, such as the move to using more digital technologies.

*"Young people may also be a good way to connect to older people also, grandparents, parents. There's a natural chain of information shared upwards from young people to grandparents and grandparents to other elderly friends."*- Deliberative workshop

# 4. Building bridges across the health and care system

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**Key takeaways**

Outside of efforts to communicate more effectively with residents across Sussex, Participants felt that greater priority should be given to **building bridges between health and care services**, to help prevent people from falling between the cracks. Participants saw opportunities for health and care professionals, VCS organisations, and residents to play a role in this.

- Suggestions included **strengthening communication between services** and **giving patients greater access and control** to their own records and information.

- Participants valued **PALS and care coordinators** and felt that extending the scope of these services to provide advice and support about all types of care, including **social care and services offered by VCS organisations**, would be beneficial.

- Participants felt that VCS organisations should be supported more, particularly if the transition to being an ICS results in **VCS services being used more frequently**.

- Participants felt that individuals could play a bigger role in supporting people in their community as volunteers. Some felt that Sussex Health and Care Partnership could provide **training to residents on how to volunteer effectively to support people in their community** to get the information and support they need.

- Participants saw an opportunity for community support networks to **connect people with lived experience**, so they can support one another.

- Participants highlighted **the growing burden on family members and carers**, and stressed the need for additional support for these people.

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## 4.1 Support to navigate health and care journeys

ICS leaders used the metaphor of 'stepping stones' to help participants visualise health and care journeys. In this metaphor, each step in a care journey, such as visiting a GP or seeing a specialist, was one stepping stone. Participants talked about barriers to moving between different points in a health and care journey so you can get stuck somewhere, or cycle between two points in the journey without making progress. Participants felt that not enough was being done to prevent people 'falling through the cracks' between stepping stones, and felt this would mean that some people weren't getting the support they need.

While most participants felt that this was partially caused by inadequate communication about how patients can navigate care and support, participants also spoke about how different services connect, communicate, and move patients between stepping stones. Participants from across the different groups, but particularly carers, spoke about the disconnect between health and social care, and the effects this can have on patients' experiences.

> *"Two big things were the stepping stones and the gaps between them. It's getting in place, as soon as possible, these people who can facilitate the moving of a person from one stone to the next one without losing them… that's key. Once that's in place it'll streamline the whole system, avoid losing people."*- Deliberative workshop

When thinking about the support that patients or carers need to navigate their health and care journeys, most participants spoke about the role of care coordinators and the Patient Advice and Liaison Service (PALS). Participants recognised that these services provide bridges that help patients and carers link together different aspects of care. Some participants felt that PALS and care coordinators could help patients have more personalised and more appropriate care experiences.

Some participants noted that the patients with the most complex care arrangements have the greatest need for support in navigating care, but the services available, such as PALS, can only provide support in navigating discrete aspects of their care. Participants wanted holistic patient support services that can provide advice about all the health and social care services that a patient needs to access, regardless of the organisation that is providing it.

> *"I also think the thing that gets missed is the person-centred approach, what people actually need beyond a one size fits all. That's where people fall through the gaps, the care plans aren't meeting people's needs."* – Deliberative Workshop

Similarly, participants spoke about the role that VCS organisations can, and do, play in supporting patients. Some participants spoke about the importance of VCS organisations in signposting patients and carers to the support they need. A few participants talked about how VCS organisations can work with care coordinators to connect different forms of care and support.

> *"As a care coordinator, you're building that link between social and healthcare systems by also signposting to VCS organisations that are providing support for that carer, so they can actually do their job, and there is that bridge that's maintained."* – Deliberative Workshop

However, these participants also felt that the relationships between VCS organisations and health and care professionals were often tenuous and informal. Most participants recognised the value of the support that VCS organisations offer, particularly during the pandemic, and wanted to see more formal relationships being established between VCS organisations and the health and care system. A few participants wanted more clarity about how VCS organisations would be

integrated within Sussex Health and Care Partnership, and felt that more could be done to ensure that the services provided by VCS organisations were properly signposted to relevant patients or carers.

*"There is a massive amount of support out there, but you have to know where to find it… For example, during pandemic, we had training courses from West Sussex Carers, one of the best charities ever to exist alongside others like Umbrella, Mind, Dementia Care."* - Carers' discussion group

However, a few participants also felt reluctant about relying on VCS organisations to provide services and support that they felt ought to be provided by the NHS. In addition, a few participants spoke about the pressures that VCS organisations were under and questioned the capacity and capability of VCS organisations to relieve wider pressures on the health and care system. These participants felt that deeper integration of VCS organisations within the health and care system needed to come with better support for these organisations, including resources and training.

## 4.2 Strengthening lines of communication between services

Some participants spoke about the lack of support for those people helping family or friends get the care they need, and the stress that holding responsibility for getting someone care brings to carers and family members. Participants often focused on both the length of time it takes to get the right care from the right people and the frustration they experience when trying to ensure this happens.

*"My mother has a complex condition, mental and physical. The biggest challenge has been dealing with multidisciplinary teams, being batted around GPs, and no one really taking responsibility. Each person you come into contact with… you don't want to be repeating the situation, [you] feel like you're going back to square one."* – Deliberative Workshop

Some participants felt particularly frustrated about having to repeatedly explain why they were seeking care to different people. This made participants feel as though they weren't being supported, that health and care professionals were reluctant to help, and that they had to justify being at appointments. This contributed to participants feeling that moving through the health and care system was burdensome and stressful.

A few participants felt that the quality of the IT systems used to share data, contributed to these frustrations. These participants felt that more could be done to improve the efficiency of data sharing. A few participants wanted to ensure that all services and organisations that provide health and care were connected via the same data sharing system, to ensure that the relevant people knew the relevant information.

*"I always wonder when I go from provider to provider how they don't have a summary sheet. For my son, for example… The personal intimate things that I don't want to talk about in front of him every single time. Sometimes a provider will know, and it's like, 'thank god… I don't have to*

*talk about it".* – Deliberative Workshop

Some participants felt strongly that patients and carers should have more ownership over their personal medical information. This would help to ensure that when patients move between points in their health and care journeys, they know that the right people have the right information. Although people with access to the internet and a personal device can now access their own medical records more easily through the NHS app[4] and other online health services[5], participants noted that not everyone can access or use these services. Participants felt that providing patients with a summary sheet, covering only relevant information, that they can take to subsequent appointments would simplify the process and help people, particularly those who are digitally excluded, to feel more in control. These participants felt that this would help ensure continuity in care between different services and systems.

Most participants recognised that the transition to becoming an ICS ought to improve how different parts of the health and care system communicated. A few participants felt that this could be communicated to the public more effectively, so that people were aware that these issues were starting to be addressed. Nevertheless, a few participants were concerned that VCS organisations would be excluded from these changes, which would mean that those people relying on the support of VCS organisations would still experience similar issues. These participants wanted to see Sussex Health and Care Partnership leading change that supported communication and collaboration with VCS organisations.

*"There are conversations happening but I'm not getting a sense of where they're going and how the partnership working filters down to the frontline and how we start working together cooperatively."* - Councillors and Community Ambassadors' discussion group

## 4.3 A role for residents to support each other

Participants also spoke about the support available at a local level. Some participants spoke about the importance of community-based advocacy and peer-support networks. These participants felt that people with lived experience offered a different perspective to patients, that complemented advice and support provided by health and care professionals.

*"What we do now is an informal thing where parents come over, one panel for autism and ADHD… we share experiences of how to navigate the system and where to seek help"* - Carers' discussion group

Additionally, these participants noted how important community-based support was for vulnerable and excluded people too. A few participants felt that peer support networks should be linked to primary care, and a few other participants noted that peer support networks could provide additional support online.

*"Also, peer to peer support online. If someone's struggling with something it can help support [them]. So, if someone's having a struggle with*

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[4] https://www.nhs.uk/nhs-app/
[5] https://www.nhs.uk/nhs-services/gps/online-health-and-prescription-services/

*something it's having that network of communication so that people can have a wider understanding of NHS services."* – Deliberative Workshop

Most participants felt that there were many people who wanted to help, but that people we unsure what they could do. These participants felt that local communities could benefit from a programme that trains residents on effective ways of volunteering. Some of these participants felt that joining community-based support networks was one way in which people could take more individual responsibility in relieving system pressures.

A few participants spoke about having local champions that mirror vaccine champions but focus instead on signposting and distributing information to help people through their health and care journeys.

Some participants felt concerned that the transition to being an ICS might reduce the focus on smaller, place-based community projects. Participants again noted the resourcing and funding challenges associated with supporting community-based projects and providing additional training. A few participants felt that closer links to housing associations, through local authorities, could help the ICS to identify areas to target with specific support for community-based projects.

However, some participants were concerned about relying on individual residents and/or family support networks to mitigate the effects of system pressures on patients. These participants felt that system pressures had knock on effects for the health of family members, who may be unable to provide the required care. These participants often spoke about their own experiences supporting family members while receiving care. A few participants described situations when relying on family support was the worst option for the patient and the family, but it was the only option available due to system pressures.

*"I've been in a situation where my mother has been discharged and it has put a huge strain on the family and it reaches a crisis point, it was assumed it would be okay because the family members were there. The health implications on the family are overlooked."* – Deliberative Workshop

In line with this, participants felt that there should be support available, particularly at the community-level, for families and friends that are responsible for helping someone they know get the care they need. These participants recognised that people might be expected to act informally or temporarily as carers, but without any help, support, knowledge, or training about what to do. Similarly, some participants also spoke about the need for improved support for carers, particularly in helping them to function as the bridge that connects together different areas of care and support.

*"The carer is the focal point of everything that happens because they are closest to the person who is in need of medical care, the first point of help and the communications hub. They need support along that process, otherwise it's just a mess… ill informed, ill dealt with by the carer."* – Carers' discussion group

# 5. Reflections on the process

This deliberative engagement programme brought together a diverse group of Sussex residents and stakeholders to learn about and reflect on the pressures facing the health and care system. Participants were able to engage directly with one another and with senior leaders from Sussex Health and Care partnership, and collectively highlighted a set of key opportunities to improve public understanding of system pressures, and to support people to navigate changing health and care services more effectively.

*"I would just like to say how enlightening it was in speaking to senior NHS employees over the course of the groups after initially thinking that it was a bit above my level of knowledge of the NHS." – Participant feedback*

Participants reported feeling listened to and valued throughout the process. A number of participants specifically referenced how they enjoyed hearing from a range of perspectives – a hallmark of deliberative engagement processes. Participants also particularly valued being able to engage directly with senior NHS leaders.

*"I loved being part of the process and felt very privileged to be able to share my thoughts and experiences. I have explained my involvement to friends and colleagues, and they have been asking if they could be part of future research, so it (the opportunity) is obviously valued within the community. I felt listened to and valued throughout and I can't wait to see what happens next!" – Participant feedback*

For the ICS leaders feeding into and participating in the programme, being involved helped them to understand the current situation from a different perspective, and to see the value in engaging with residents in this way, highlighting the potential for future programmes to continue to surface useful insight for decision-makers across the ICS.

*"As Urgent and Emergency Care programme director, I am acutely aware on a day-to-day basis of the pressure the system is under and can assume the impact this has on our patient population. With very little direct patient involvement myself I wanted to be part of this process so I could better understand impact from a patient perspective and have a fresh lens on what we can do differently"- Maggie Keating, Urgent and Emergency Care programme director*

# 6. Conclusion and next steps

This deliberative engagement programme supported senior leaders within the ICS to form a dialogue with a diverse group of Sussex residents and other key stakeholders. They explored some of the pressures in the health and care system, and the impact on individuals and communities. These discussions have highlighted a range of important considerations and potential actions for system leaders and their teams to review and consider, in relation to the following areas:

- Building and maintaining trust and confidence in health and care services through open communication and dialogue - continuing to keep people informed about the status of different parts of the health and care system, and the ways in which people can support themselves and their communities.
- Getting the right information to the right people through varied and tailored initiatives, without relying too much on social media.
- Building bridges across the health and care system by leveraging existing roles and communication channels and supporting people to volunteer more effectively.

As the health and care system continues to respond and adapt to changing pressures, the findings from this programme can feed into ongoing planning activities. Key next steps include:

- A Routes to Action meeting with wider health and care service leaders in early February 2022 will provide space to discuss the implications of these findings, and highlight key opportunity areas for progressing ideas and suggestions into action plans.
- This report, and a summary of discussions in the Routes to Action meeting will be shared with participants.
- System leaders will then align actions with existing plans, workstreams and programmes, to support the progression of ideas and suggestions arising from this process.

Supporting ongoing discussions with people and communities is a priority for the ICS, and Sussex Health and Care Partnership's public involvement team will ensure there is an opportunity for those who have participated in this deliberative programme to come together later in 2022, to hear about progress and opportunities to stay involved.

# Appendices

## Appendix A: Participants and recruitment

Overall, 47 people participated in the deliberative engagement programme. These groups of people were a mix of people from Sussex and professional stakeholders of SHCP (VCS & Councillor groups). Below is a table showing the level of involvement from the different discussion groups in each stage of the project. It also shows how we recruited each group.

**Breakdown of participation in deliberative workshop by discussion group:**

| Group | Number in discussion groups (47 in total) | Recruitment approach | Number in Deliberative Workshop (16 in total) |
|---|---|---|---|
| Mixed public groups | 16 | Fieldwork agency | 4 |
| People from minority ethnic backgrounds | 7 | Survey distributed to SCHP partners | 4 |
| Young people | 7 | Survey distributed to SCHP partners | 3 |
| Carers | 5 | Survey distributed to SCHP partners | 2 |
| VCS & Healthwatch | 7 | Through SHCP network | 1 |
| Councillors & Community Ambassadors | 5 | Through SHCP network | 1 |

## Appendix B: Process plan

Below are the process plans for each phase of the project. Starting with the briefing session, then discussion workshop and finally, the deliberative workshops. The process plans outline the activities undertaken, timings, and materials used to deliver each session.

## Phase 1: Information session

| Time | Activity |
|---|---|
| **6pm**<br>(10 mins) | **Welcome and introductions** |
| **6:10pm**<br>(20 mins) | **The context:** Key system pressures, what this means for patients and for staff, and how these pressures relate to / influence each other<br><br>**Why we're starting this conversation:** Key questions we will be exploring with participants |
| **6:30pm**<br>(5 mins) | **What will happen after today:** Summarise next steps in the process |
| **6:35**<br>(20 mins) | **Q&A**<br><br>Prompts:<br>• Do you have any questions for [ICS leaders] based on their presentation / what they shared about system pressures?<br>• Do you have any questions about the process itself, or what is expected of you?<br>• Is there anything that you feel we haven't covered in this briefing, or anything that you would like more information about? |
| **6:55**<br>(10 mins) | **Next steps and close** |

## Phase 2: Discussion workshop

| Time | Activity |
|---|---|
| **6pm**<br>(10 mins) | **Welcome and introductions** |
| **6:10pm**<br>(5 mins) | **Briefing summary**<br><br>Short re-cap of the briefing material on system pressures. |
| **6:15pm**<br>(10-15 mins) | **Plenary**<br>• How do you feel about the information in the briefing about the challenges local health and care services are facing? |

| | |
|---|---|
| | • Did you already know about these challenges, or was anything new/surprising?<br>• Do you have any additional questions about these system pressures? |
| **6:30pm**<br><br>(15-20 mins) | **Activity 1: Health and care during the pandemic**<br><br>Participants' responses captured on a Jamboard. Prompts given one at a time, in order.<br>• How do you think people's experiences of health and care services have changed over the course of the pandemic? |
| **6:45pm**<br><br>(5 mins) | **Plenary**<br><br>Check back in with participants - how are they feeling so far? Do they have any questions? |
| **6:50pm**<br><br>(5 mins) | **Introduce activity 2: System Pressures**<br><br>Read through the patient story provided in the facilitator plan. |
| **6:55pm**<br><br>(5 mins) | **Break** |
| **7:00pm**<br><br>(15 mins) | **Activity 2: System Pressures**<br><br>Capture responses on a Jamboard, which contains the different pressure points.<br>• In the previous activity, when thinking about how health and care services changed during the pandemic, did the group focus more on one pressure point?<br>• Thinking about the different pressure points in turn, how do you think winter might put additional strain on each?<br>• Thinking about the different pressure points in turn, if one pressure point was unable to cope with the additional stress of winter, what would happen? |
| **7:20pm**<br><br>(40 mins) | **Activity 3: Relieving Pressure**<br>• Where do you think responsibility lies for addressing system pressures? / Whose responsibility do you think it is to ensure that the system can cope with these pressures? [Ask this question before following questions]<br>• What do you think those within health and care services could be doing to help reduce pressure on the system?<br>• What do you think individuals could be doing to help reduce pressure on the system? |
| **7:50pm**<br><br>(5 mins) | **Closing plenary** |

## Phase 3: Deliberative workshop

| Time | Activity |
|---|---|
| **12:30pm**<br>(10 mins) | **Introductions and ice breaker activity** |

| | |
|---|---|
| **12:40pm**<br>(10 mins) | **Welcome**<br>Welcome from Jane and Jessie |
| **12:50pm**<br>(30 mins) | **Activity 1: Build on emerging findings**<br>An activity to foster discussion around key findings from discussion workshops. |
| **1:25pm**<br>(5 mins) | **Break** |
| **1:35pm**<br>(1 hour 25 mins) | **Activity 2: Changes and challenges**<br>A carousel activity to explore three key challenge areas in more detail, and to surface ideas and actions to address system pressures.<br>Navigating changing health and care services (Maggie and Tom)<br>Supporting individuals and communities to take action (Jane and Maddy)<br>Joining up health and care journeys (Amy, Claire, and Jessie) |
| **2:55pm**<br>(10 mins) | **Break** |
| 3:05pm<br>(45 mins) | **Activity 3: Ideas and actions**<br>An activity to prioritise and reflect on ideas and actions that have emerged through the workshop. |
| **3:50pm**<br>(10 mins | **Close**<br>Closing reflections from Amy, Maggie, and Claire<br>Final thank you from Jane and Jessie |

## Appendix C: Involvement of ICS leaders

Below is a table showing the members of Sussex Health & Care Partnership who contributed their expertise towards the project. The table outlines their role as well as which stage(s) of the project they worked on.

| Name | Job Title | Role |
| --- | --- | --- |
| **Jane Lodge** | Associate Director of Public Involvement and Community Partnerships | SHCP Project lead, Briefing Session, Observer, Discussion Workshops, Deliberative workshop |
| **Antonia Bennett** | Head of Public Involvement | Observer, Discussion Workshops |
| **Maggie Keating** | Urgent and Emergency Care Programme Director | Briefing Session, Deliberative workshop |
| **Amy Galea** | Executive Director Primary Care | Briefing Session, Deliberative workshop |
| **Tom Gurney** | Executive Director of Communications and Engagement | Briefing Session |
| **Kerry Lloyd** | Deputy Chief Nursing Officer | Briefing Session |
| **Dr Claire Woolcock** | Medical Director – Mental Health, Transformation | Deliberative Workshop |

# Appendix D: Briefing slides

Below are slides from the participant briefing sessions. They outline challenges facing SHCP and why the project is happening.

## Pressures on the health and care system in Sussex

TRAVERSE

| More and growing need for health and care services, due to COVID-19, winter pressures | Reduced capacity in the system due to staffing pressures (not enough staff) and service changes | In places, strained relationship between the public and health and care services |

**For Sussex residents, this means…**
Backlog of waiting lists
Difficulties accessing care (from GP and A&E, mental health services, social care)

**For the NHS workforce, this means…**
High levels of exhaustion and burn out
New ways of working and service changes in response to COVID-19

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## Pressures on the health and care system in Sussex

TRAVERSE



## Priorities for winter 2021/2022

TRAVERSE

- To maintain **patient safety** at all times
- To prepare for **increased demand**
- To ensure **discharge processes** are prompt, smooth and responsive
- To ensure people are **supported after they leave** hospital
- To support **prevention in communities** to avoid hospital admission
- To ensure people have **the right information** about access to advice and support
- To continue to protect against **COVID-19 and Flu**
- Increased capacity in **111 and 999 services**

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## Why are we having this conversation?

TRAVERSE

To explore people's different **experiences, priorities and ideas** in relation to these challenges.

To reach a **collective understanding** of the situation that helps us find a way forwards.

To support **open and honest** conversations between members of the public, stakeholders and system leaders about how we can address these challenges.

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# Appendix E: Feedback poll results

At the end of the deliberative session participants were asked to answer a short poll. The poll asked a few questions assessing the mood after finishing the workshop. Participant were asked four questions and could answer: 'Strongly Agree', 'Agree', 'Disagree', 'Strongly Disagree'. The results are outlined below:

|  | Q1. I felt comfortable contributing to discussions. | Q2. I feel that my views have been adequately heard today. | Q3. I can see the value of today's discussions. | Q4. I found today's discussions useful. |
|---|---|---|---|---|
| **Strongly Agree** | 11 | 8 | 9 | 5 |
| **Agree** | 1 | 4 | 3 | 6 |
| **Disagree** | 0 | 0 | 0 | 1 |
| **Strongly Disagree** | 0 | 0 | 0 | 0 |

TRAVERSE