healthwatch
in Sussex

Improving the Outpatient experience: Patient feedback from deliberative engagement workshops April–May 2023

Healthwatch in Sussex would like to thank everyone who attended and contributed to the discussions during the workshops.

Michelle Kay

Michelle@hwbh.co.uk

Healthwatch Brighton and Hove on behalf of Healthwatch in Sussex

September 2023

1. Executive Summary

Healthwatch in Sussex[1] was commissioned by NHS Sussex[2] to run workshops with the purpose of gaining participant views on new initiatives being explored to improve the Outpatient experience. Healthwatch Brighton and Hove led the project, supported by colleagues in East and West Sussex. 31 participants attended from across Sussex, representing people who had attended an outpatient appointment and those people on the outpatient waiting list. Participants represented a diverse profile in age, ethnicity, sexuality, and health needs.

The purpose of the workshops was to review four proposed initiatives to transform the outpatient experience, as part of NHS England's Outpatient Recovery and Transformation Programme[3], namely:

- **Advice and Guidance (A&G):** This enables GPs to seek advice and guidance from consultants about diagnosis and treatment, with the potential that the patient need not visit the hospital but be treated in the local community.
- **Utilising system capacity inclusive of Patient Choice (Patient Choice)[4]:** This is where an alternative referral location could be offered to patients, which may enable them to see a consultant quicker. However, the provider offered may be in a variety of locations, sometimes outside of the local area.

---

[1] Healthwatch in Sussex is a collaboration between Healthwatch Brighton and Hove, Healthwatch East Sussex, and Healthwatch West Sussex.

[2] The Outpatient Transformation Team, at NHS Sussex commissioned Healthwatch in Sussex.

[3] For further information on NHS England's Outpatient Recovery and Transformation Programme, please see https://www.england.nhs.uk/outpatient-transformation-programme/

[4] Utilising System Capacity was the term used throughout the workshops and one with which all participants became familiar. However, following the workshops NHS Sussex advised that the term Patient Choice was a more familiar term used within the NHS and therefore both terms have been used in this report.

- **Patient initiated follow-up (PIFU):** After the initial consultant appointment, usually a patient would be given a follow-up appointment on a set date and time. Instead, PIFU gives the responsibility of follow-up to the patient, where they decide if and when they need an appointment. They are then expected to proactively telephone (using a number provided in advance) and make their own booking for a follow up appointment.
- **Reducing 'Did not attends' (DNAs):** DNAs are the name given to patients who do not turn up to appointments, costing the NHS time and money[5]. NHS Sussex were interested in participants' views about why this might happen and how to prevent this happening.

Workshops followed a deliberative engagement methodology which focused on increasing participant knowledge of the outpatient system and enabling them to make an informed judgement of the transformation options proposed. Participants were encouraged to view the transformation from others' perspectives as well as their own, by being provided with scenarios and encouraged to listen to other perspectives in their discussion groups. The majority of workshop time was given to participant discussion and feedback.

"Thank you for the opportunity to attend the workshops. I got more from the workshop than I had thought I would to be honest. I found the method used throughout meant I was met at my level of competency, without assuming what I would/wouldn't be able to understand. Being more open to sharing information prior to each session allowed me to give more considered and meaningful feedback.

There is often a perception that documents shouldn't be shared until they are the finished version, however this process demonstrated willingness to learn from participants, rather than tell and get this

---

[5] At the time of the workshops, it was estimated by NHS Sussex, that 75,000 patients DNA their appointment each year, costing the NHS £160 per appointment.

signed off. The time for more active discussions and listening gave people the space to learn from each other. This process for me has helped me reflect on how I engage with people within my professional role too."
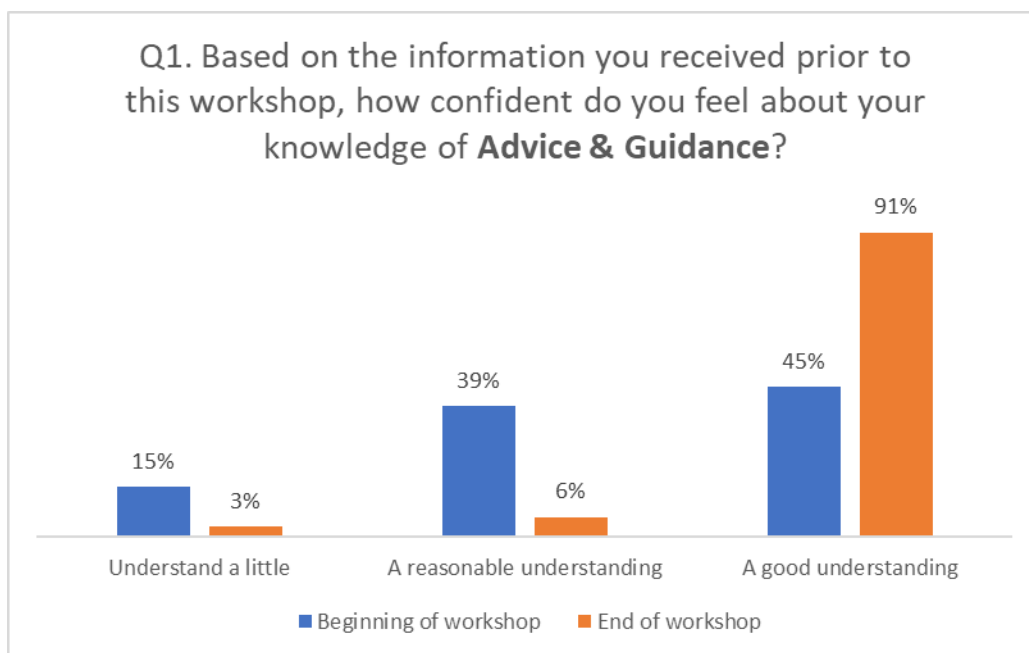*Participant comment on the benefits of the deliberative engagement methodology used in the outpatient workshops.*

Healthwatch Brighton and Hove convened and chaired the workshops and maintained contact with each participant throughout the process. In addition to a robust screening process for recruiting participants, the relationship building ensured that only two participants dropped out from the process (due to ill health).
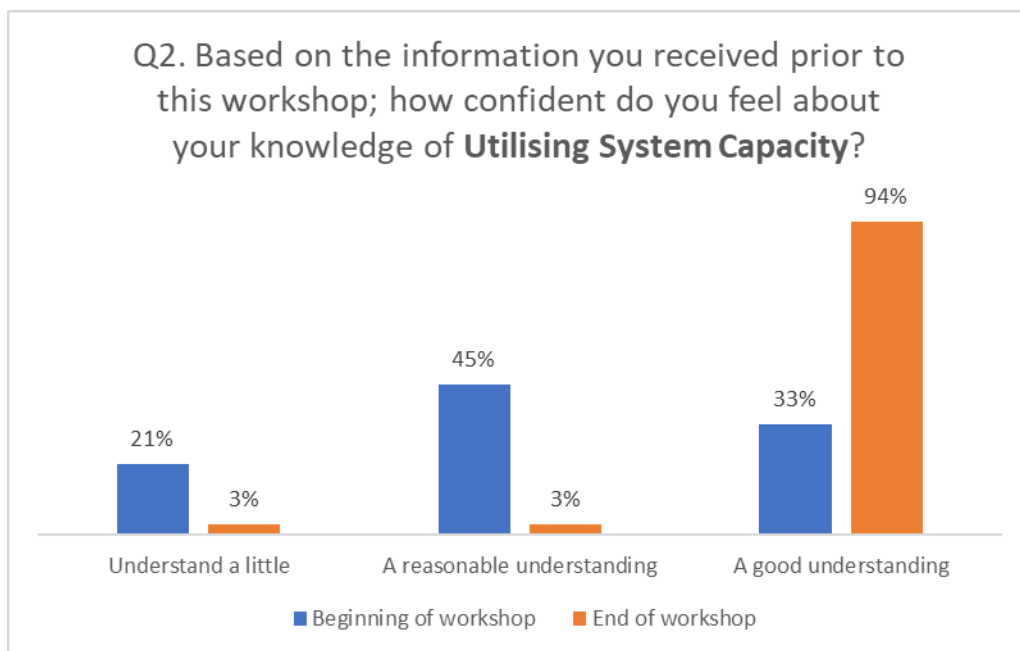
Results from online polls held at the beginning and end of workshops 2 and 3 showed a significant growth in participant knowledge about the outpatient transformation system.

Workshop 2 covered Advice & Guidance and Utilising System Capacity (Patient Choice) and the graphs below show how the participants responded to the question about their understanding of the respective topic areas at the beginning and end of the workshop.

Question 1 demonstrated that under half (45%) of participants felt they had a *good* understanding of Advice & Guidance at the beginning of the workshop; by the end of the workshop, 91% of participants felt that had a *good* understanding of this topic area.

Q1. Based on the information you received prior to this workshop, how confident do you feel about your knowledge of **Advice & Guidance**?
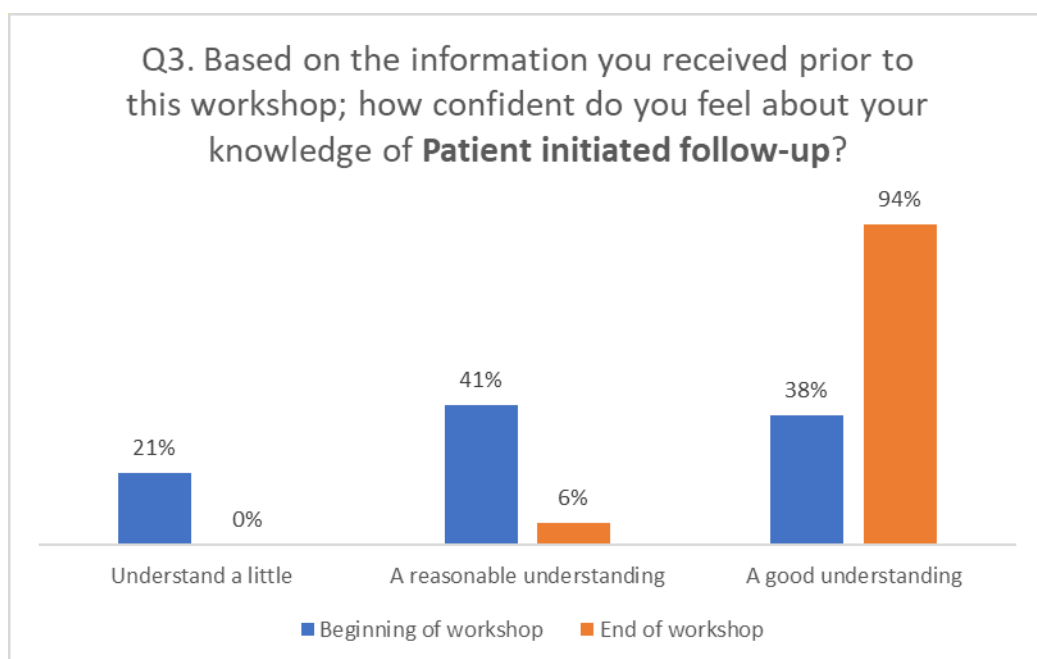
Question 2 demonstrated that the majority (45%) of participants felt they had a *reasonable* understanding of Utilising System Capacity (Patient Choice) at the beginning of the workshop; by the end of the workshop, 94% of participants felt that had a *good* understanding of this topic area.

Q2. Based on the information you received prior to this workshop; how confident do you feel about your knowledge of **Utilising System Capacity**?

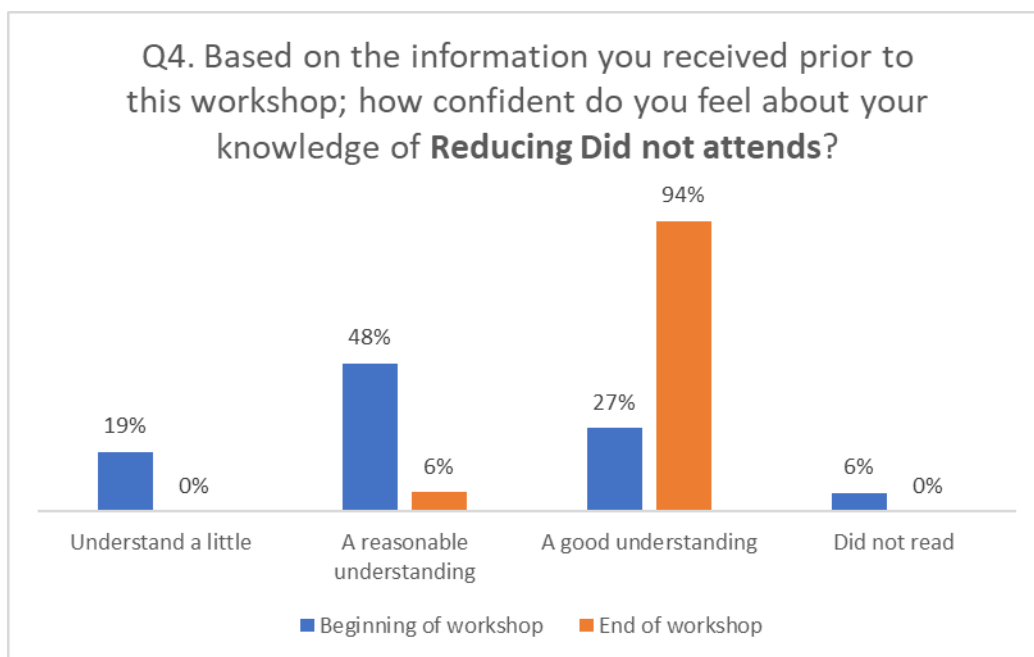|	Understand a little	A reasonable understanding	A good understanding
Beginning of workshop	21%	45%	33%
End of workshop	3%	3%	94%

Workshop 3 covered Patient initiated follow-up and Reducing Did not attends and the graphs below show how the participants responded to the question about their understanding of the respective topic areas at the beginning and end of the workshop.

Question 3 demonstrated that under half (41%) of participants felt they had a *reasonable* understanding of PIFU at the beginning of the workshop; by the end of the workshop, 94% of participants felt they had a *good* understanding of this topic area.

Q3. Based on the information you received prior to this workshop; how confident do you feel about your knowledge of **Patient initiated follow-up**?

Question 4 asked about participant knowledge of DNAs. Two people admitted they had not read the information in advance of the workshop. Of the remaining participants, almost half (48%) felt they had a *reasonable* understanding of the topic at the beginning of the workshop; by the end of the workshop, 94% of participants felt they had a *good* understanding of this topic area.

Q4. Based on the information you received prior to this workshop; how confident do you feel about your knowledge of **Reducing Did not attends**?

	Understand a little	A reasonable understanding	A good understanding	Did not read
Beginning of workshop	19%	48%	27%	6%
End of workshop	0%	6%	94%	0%

■ Beginning of workshop   ■ End of workshop

This was central to the deliberative engagement approach, confirming whether participants were gaining knowledge from the process. NHS Sussex noted participants' growing confidence in giving their opinions in an informed way without needing to clarify meanings and understanding.

Participant engagement became less about personal experiences and more about the wider patient experience. This was encouraged by providing participant information in advance, giving informative presentations, sharing scenarios from the perspective of different types of people and ensuring participants heard from one another who represented a diverse participant profile. More can be read about the deliberative engagement methodology in Section 4.

Participants were rewarded with a financial incentive and offered the opportunity to participate in for further engagement with NHS Sussex following the workshops.

Participants brought their own experiences to the workshops. Examples included difficulties with booking systems and waiting times; and a shared frustration with the lack of communication received as a patient once in the system. Participants spoke about the lack of time for medical staff to understand and treat the patient as an individual.

Participants were split into four discussion groups, with each given different scenarios or sample patient information to look at. However, views expressed were often similar across the discussion groups.

- Participants thought Advice & Guidance made good sense in theory but were concerned that some conditions and some individuals were not suitable for this system.

- Participants felt that Utilising System Capacity (Patient Choice) could help respond to local demand pressures. However, if the offer is further away than the patient's local hospital, this may exclude some patient groups.

- Participants felt Patient Initiated Follow-up (PIFU) was a good example of giving patients some control over their own healthcare journey. However, some patients would need additional support and for other patients, PIFU may not be suitable.

- Participants disagreed with one another about patient responsibility around reducing Did Not Attends. Some participants felt that DNAs should go to the bottom of the waiting list. Other patients suggested that financial and deprivation reasons caused patients to DNA.

Some findings related to some or all of the initiatives discussed:

- As the patient journey started with the GP, participants stressed how important it was for the GP to be up to date with information, to give time to listen and respond empathetically to patients. Where patients had additional needs or needed extra support, this should be noted on patient records and play a role in the way they were treated throughout their healthcare journey.

- Participants were shown several samples of NHS patient information, and similar observations were raised across all the examples. Information was often lengthy and unclear; some practical information was not included, and not enough emphasis was given to the important facts that patients needed to know. Co-production with patients could benefit development of future patient information and any related communication.

- Participants felt publicity for introducing service changes to the outpatient system, should be widespread, in various formats, and local organisations could be helpful in promoting this.

In summary, to ensure the transformation of outpatient services was effective participants felt patients should be kept at the heart of all proposed initiatives.

> *"Patients should not be passive recipients of healthcare. But rather active users who are prepared to give their opinion and ensure they influence the service they receive. For example, I have spoken to my MP in the past where I have had challenges with my healthcare service, and she has been influential in ensuring my concerns are heard by decision-makers." Participant comment on effective patient involvement.*

Healthwatch in Sussex made seven recommendations resulting from these findings, and these are presented in the next section.

2. Recommendations

Based on the findings above, Healthwatch in Sussex recommends the following to the Outpatient Transformation Team, at NHS Sussex:

1. **Involve patients in their care.**
   Participants felt this was key to all initiatives, from involving the patient when making a diagnosis and planning treatment to finding out a patient's preferred form of appointment and communication. Participants suggested that Advice and Guidance became a three-way conversation involving the patient, GP, and any specialists involved in organising their treatment (e.g. consultants). Participants also suggested patient information and correspondence could benefit from being co-produced with patients.

   Utilising System Capacity (Patient Choice) and Patient Initiated Follow Up were both seen as positive in offering the patient some element of control over their own care. However, patients should also be given the option not to use these initiatives, and where relevant informal carers such as family members and friends should also be involved in decisions about which initiatives to pursue.

2. **Communicate with the patient throughout their journey.**
   Participants felt that lack of appropriate communication was one of the biggest frustrations for patients. Patients should be kept updated concerning waiting times for diagnosis, referrals, and appointments. Patients should be kept up to date on where they are in the treatment lifecycle.

3. **Ensure GPs are aware of and trained accordingly in all new healthcare initiatives.**
   Participants stressed the importance of the GP as the first point of contact for healthcare. GPs should be made aware of any new healthcare initiatives and trained accordingly. Where patients need extra support, this should be noted on the GP patient record and maintained throughout the patient journey. This should include full medical notes, including current treatments and appointments,

particularly where comorbidity is present and could affect future treatment choice.

Participants also stressed the importance of including "personal notes" on a patient's record, which may help identify any flexibility or restrictions on attending appointments, or communicating with the patient. For example, whether the patient drove, and/or had a car, whether they cared for another person, adult, or child, or had other responsibilities. Also, the patient's preferred communication format (email, letter, phone call) and preferred appointment format (face to face or virtual).

4. **Take patients individual needs into consideration and adapt care, communication, and treatment accordingly.**
Participants agreed that some of the transformation initiatives might not work for every patient. Some conditions need to be seen in person and cannot rely on second hand communication via the GP, through the Advice and Guidance initiative. Patients with additional needs may not be suitable for initiatives that relied on the patient proactively following up. Utilising System Capacity (Patient Choice) may not be suitable for patients with accessibility challenges (e.g. mobility issues, without their own transport, and/or located far from public transport). Up-to-date patient records mentioned above would help identify patients' individual needs.

5. **Ensure the infrastructure supports the transformation.**
   o Participants agreed that a robust infrastructure was needed to ensure the success of the transformation.
   o For Advice and Guidance to work, consultants need adequate time and capacity to respond to GP requests.
   o For Patient Choice to work, there needs to be continuity of care between local NHS services and those in other locations, including access to patient records with any additional needs noted.
   o For Patient Initiated Follow Up (PIFU) to work, telephone lines need to be staffed and responsive, preferably with a dedicated PIFU telephone number separate from other booking lines. Patients should be able to leave a voicemail message during non-office

hours, and be confident that any message left will be responded to.

- o For Did Not Attends (DNAs) to be reduced, cancelled appointments should be offered to other patients, and an effective system should be in place for patients to cancel or postpone an appointment. Consideration should also be given to patient involvement in the process for booking appointments at dates/times convenient to them in the first place.

6. **Provide clear, concise patient information.**
Participants agreed that patient information should be clear and concise, emphasising the most important information (appointment time, date, medical speciality etc.,). Where relevant, practical information (e.g., transport links to hospital locations) should be separated either on the back of letters or in a separate leaflet. In the PIFU and DNA sample patient communications shared with participants, information was often mixed up making it difficult to identify the most important details.

Participants felt verbal explanation describing the next steps should accompany any written information to allow the patient to clarify anything they have not understood. Visual aids, such as maps and pictures should be included where possible to increase accessibility.

7. **Publicise the transformation widely and in accessible formats.**
Participants suggested that communicating the proposed transformation of outpatient services should be widespread, both nationally and locally, and made available in health and non-health related locations. Information should be in a range of formats, digital and traditional. NHS Sussex would benefit from partnering with local organisations to help publicise the changes as well as directly engaging with patients themselves. All staff should be trained and informed in the new initiatives, and GPs should be kept up to date.

3. Introduction

"We really wanted to understand what matters to patients and how we need to adapt our programme accordingly. These workshops were well attended with all participants making a valuable contribution. The discussions and points raised were really interesting and of huge value to our programme plan going forward. Overall, the workshops and deliberative engagement process exceeded our expectations and we are incredibly grateful to everyone involved."
Outpatient Transformation Team

"I found the whole process interesting and very informative - from the presenters and from the comments of other participants. I'd like to think I now have a better insight into the workings, and the challenges, of the outpatients' system." Participant

Healthwatch in Sussex[6] was commissioned by the Outpatient Transformation Team within NHS Sussex (for ease, 'NHS Sussex' will be used as reference from now on) to capture the views of previous and current users of outpatient services on new initiatives being introduced to enhance the Outpatient experience.

We used a deliberative engagement approach, which is explained in more detail under section 2: Methodology. In this deliberative engagement approach, most of the engagement time is given to participant discussion rather than presentations by experts; increasing participant knowledge through new information; enabling direct engagement between participants and decision makers; and encouraging further engagement beyond the project lifetime. Participants needed to be open to evaluate the initiatives from other viewpoints, as well as from their own experience.

---

[6] Healthwatch in Sussex is a collaboration between Healthwatch Brighton and Hove, Healthwatch East Sussex, and Healthwatch West Sussex.

"I did enjoy the deliberative engagement process. A great deal can be learnt if people are prepared to share their real views about things and learn how things work. It is even better if ordinary service users can have some influence on how services are designed." Participant

Healthwatch in Sussex was tasked with recruiting between 22 and 35 people from across Sussex to participate in four workshops. The purpose of the workshops was to review four proposed initiatives to transform the outpatient experience, namely:

- **Advice and Guidance (A&G):** This enables GPs to seek advice and guidance from consultants about diagnosis and treatment, with the potential that the patient need not visit the hospital but be treated in the local community.

- **Utilising system capacity inclusive of Patient Choice (Patient Choice)[7]:** This is where an alternative referral location could be offered to patients, which may enable them to see a consultant quicker. However, the provider offered may be in a variety of locations, sometimes outside of the local area.

- **Patient initiated follow-up (PIFU):** After the initial consultant appointment, usually a patient would be given a follow-up appointment on a set date and time. Instead, PIFU gives the responsibility of follow-up to the patient, where they decide if and when they need an appointment. They are then expected to proactively telephone (using a number provided in advance) and make their own booking for a follow up appointment.

- **Reducing 'Did not attends' (DNAs):** DNAs are the name given to patients who do not turn up to appointments, costing the NHS time and money[8]. NHS Sussex were interested in participants'

---

[7] Utilising System Capacity was the term used throughout the workshops and one with which all participants became familiar. However, following the workshops NHS Sussex advised that the term Patient Choice was a more familiar term used within the NHS and therefore both terms have been used in this report.

[8] At the time of the workshops, it was estimated by NHS Sussex, that 75,000 patients DNA their appointment each year, costing the NHS £160 per appointment.

views about why this might happen and how to prevent this happening.

Participants needed to either have had an outpatient appointment or were on the waiting list for an outpatient appointment.

"I learnt that with new technology we can help patients get a much more efficient service and choice from our NHS. Please continue research on patient accessibility to NHS service needs to ensure that all patients can understand all the options available to them." *Participant comment*

Participants were expected to feedback on whether the initiatives could work for all patients or whether they may cause barriers for some. Participants were also encouraged to suggest what support might be needed for the initiatives to work effectively. The workshops were one of several ways NHS Sussex were engaging with patients regarding the outpatient experience and Healthwatch in Sussex were also asked to find out if participants would be willing to continue their engagement with NHS Sussex beyond these workshops.

Recruitment

Healthwatch Brighton and Hove led the project recruiting 33 participants with the support of Local Healthwatch in East and West Sussex. Participants represented a diverse profile, with variations in age, ethnicity, sexuality, and health needs. Some participants had attended, and some were waiting for, an outpatient appointment. Some participants had attended one appointment and were waiting for another. A full participant profile can be seen in Section 4.

Healthwatch Brighton and Hove carried out a robust screening process, using qualitative questions over email. We also individually telephoned each applicant to inform them about the project as well as ensuring applicants were fully committed to the project. Screening questions

were shared with Healthwatch West Sussex who helped recruit people from their local area.

Once recruited, Healthwatch Brighton and Hove kept contact with all participants, providing pre-workshop information, reminders during the workshops and sending any additional information required. As a result of the screening process and relationship building with participants, the majority of participants attended all workshops. Two people did not attend any of the workshops and two people missed one workshop each, all due to ill health. This resulted in 29 people who completed all four workshops, and two people who completed three workshops each. Please see the methodology section for further information.

Workshop facilitation

Healthwatch Brighton and Hove convened and chaired the four workshops in April & May 2023. We worked closely with NHS Sussex, meeting weekly, to agree all arrangements. Four breakout groups were agreed in advance, for each workshop.

Healthwatch Brighton and Hove recruited experienced staff & volunteer facilitators, including one staff member from each of the three local Healthwatch, (East Sussex, West Sussex, and Brighton and Hove) and a shared facilitation between two Board Directors from Healthwatch Brighton and Hove.

We also organised note-takers for each breakout, from East Sussex, and volunteers from Healthwatch Brighton and Hove. Technical support was shared between Healthwatch East Sussex and Healthwatch Brighton and Hove. Healthwatch Brighton and Hove ran briefing sessions, and produced written guidelines, for facilitators and for note-takers, ensuring recordings were available for any facilitator or note-taker who was unable to attend.

Participant information

Working with NHS Sussex, Healthwatch Brighton and Hove provided the 31 participants in attendance with information on the outpatient system before, during and between each workshop. Participants were expected to read all material and watch any videos and prepare answers to any questions in advance, ensuring they were ready to participate in the workshop discussions. Healthwatch Brighton and Hove formed strong communication lines with each participant, sending weekly emails and meeting links, providing advice and explanation, and answering individual clarification questions.

At the beginning of each workshop, Healthwatch Brighton and Hove welcomed everyone individually ensuring they could be heard and seen and were able to fully participate in the session. Any technical or other issues were supported to ensure full attendance.

Four initiatives were covered by these workshops:
- Advice and Guidance (A&G);
- Utilising system capacity (Patient Choice);
- Patient initiated follow-up (PIFU); and
- Reducing 'Did not attends' (DNAs).

It was agreed between Healthwatch Brighton and Hove and NHS Sussex that the first workshop would allow patients to talk about their personal experiences and receive feedback on complaints/suggestions for improvement from NHS Sussex. This also enabled later workshops to focus on the transformation initiatives. The fourth workshop focused on communicating the proposed transformation to the wider public and Healthwatch Brighton and Hove suggested that this also included a "what's next?" presentation by NHS Sussex.

Results from online polls and observations by NHS Sussex concluded that the deliberative engagement process had increased participant knowledge in the outpatient system and confidence in giving their

opinions in an objective and informed way and more can be read on this methodology in the next section.

Following the workshops, participants were provided with a £100 voucher as a thank you for their time and involvement in the workshops. Healthwatch Brighton and Hove kept in touch with participants following the workshops, to encourage further participation in patient engagement run by NHS Sussex. We also proposed that participants should have sight of the findings of the workshops before NHS Sussex, in order to give feedback that may be incorporated into the final presentation.

The next section describes the deliberative engagement process, followed by the participant profile and the participant information provided prior to the workshops (pre-workshop information). Subsequent sections outline the findings per Workshop as follows:

- Workshop 1 Participant experiences of the outpatient system and suggestions for improvements
- Workshop 2 Advice & Guidance (A&G)
- Workshop 2 Utilising System Capacity (Patient Choice)
- Workshop 3 Patient Initiated Follow-up (PIFU)
- Workshop 3 Reducing Did Not Attends (DNAs)
- Workshop 4 Suggestions for a better system
- Workshop 4 Communicating the outpatient transformation to the wider public.

The final sections are the Conclusion and Appendices.

4. Methodology - Deliberative Engagement

The outpatient workshops differed from previous workshops, conferences, and webinars Healthwatch Brighton and Hove have organised, by using a deliberative engagement method. The following references the principles of deliberative engagement methodology as set out in the National Consumer Council (2008) *Deliberative public engagement: nine principles[9]* and demonstrates how the outpatient workshops met these principles. For ease of reading, from this point forward, Healthwatch Brighton and Hove will be referred to as HWBH.

In summary, the outpatient deliberative engagement workshops differed in several ways to previous engagement work, namely:
- An emphasis on providing new information to participants and increasing their knowledge of the outpatient system, creating outpatient "experts".
- An emphasis within the workshops on participant discussion and feedback, rather than presentations by HWBH or NHS Sussex.
- Ensuring the objective of the workshops was clear and demonstrating how participants had contributed to this.
- Giving participants the opportunity to feedback on workshop findings, and influence recommendations within this final report.
- Encouraging participants to offer further engagement beyond the workshops, through direct patient engagement with NHS Sussex, in addition to the usual offer of working with one of the local Healthwatch again in the future.

---

[9] https://involve.org.uk/sites/default/files/field/attachemnt/Deliberative-public-engagement-nine-principles_1.pdf

In more detail and using the deliberative engagement principles laid out in the National Consumer Council (2008) *Deliberative public engagement: nine principles[10],* the following demonstrates how the outpatient workshops met these principles.

What is deliberative engagement?
The deliberative engagement methodology is about giving participants time to consider and discuss an issue in depth before they come to a considered view.

It was important that the workshops ran over the course of several consecutive weeks (in this case four), and that participants were available for the entirety of those four weeks. It was also important that the four discussion groups maintained the same people for the whole four weeks, so that participants could learn from one another and develop ideas together, as they became more comfortable as a group.

HWBH worked with NHS Sussex to ensure all participants received information before each workshop, were informed about the topics, and came prepared to discuss them. The format of the workshops emphasised group discussion, giving most of the time to this and feedback to the main group, while a small amount of time was given to presentations by HWBH and NHS Sussex.

What does Deliberative Engagement involve?
Deliberative engagement participants should be enabled to gain new information and discuss implications of their new knowledge in terms of their existing attitudes, values, and experience.

HWBH provided participants with new information from NHS Sussex about each of the proposed initiatives: Advice & Guidance; Utilising System Capacity (Patient Choice); Patient initiated follow-up; and Reducing Did Not Attends. For the new initiatives, participants were also given sample patient letters to demonstrate the type of information that is being currently received by patients, and offering the chance for participants to discuss how these could work and make suggestions for improvement.

---

[10] https://involve.org.uk/sites/default/files/field/attachemnt/Deliberative-public-engagement-nine-principles_1.pdf

NHS Sussex also provided a presentation on the initiatives at the beginning of each workshop which gave further information.

Deliberative engagement involves working with a range of people and using information sources from a diverse range of people and views.
Healthwatch in Sussex recruited people with a range of diversity in age group, health condition, ethnic background, and gender (see participant profile). HWBH and NHS Sussex also provided participants with scenarios so that participants could consider the outpatient experience from the perspective of other patients with a particular need or from a particular health inequality.

Participants were asked to consider whether the initiatives could work for these patients or whether there were barriers and how these might be overcome. Participants were also encouraged to reflect on their own experiences as well as listen to others from their group, and to approach their discussion in a non-judgmental way to be able to consider different

---

Shared Agreements in the workshops
We will try to…
- Be curious about and respect other people's opinions, even when we may not agree with them.
- Make sure everyone has a chance to contribute.
- Be present and engaged during sessions, switch off distractions.
- Respect each other's differing needs and experiences.
- Ask, if we need help or clarification.

---

viewpoints. HWBH proposed shared agreements to reinforce this approach.

Deliberative engagement involves a clear task or purpose, relating to influencing a specific decision, policy, service, project, or programme.
In this case, the outpatient transformation plan and the four initiatives as described above were explained to all participants. Participants were advised that their feedback was one important part of patient engagement that was being carried out by NHS Sussex, who set out some goals for the participants in the first workshop, namely to:
- Draw on your own experiences

- View the programme plans from other perspectives
- Help to inform patient materials
- Opinions and ideas on key areas
- Open and honest discussion.

What makes deliberative engagement different?

Deliberative engagement emphasises the public (in this case, patient) attitudes and values. Participants were asked to share their own experiences as well as think about the way in which other patients engage with the outpatient system. Participants were given the time to discuss their thinking and feedback to NHS Sussex directly. HWBH ensured that each discussion group had an experienced facilitator to lead, and ensure every group member had a chance to speak and were listened to by others. Facilitators were also asked to feedback their groups' key points to the main room following the discussion. HWBH assigned a note taker to each discussion group, so that points raised were recorded for inclusion in the final report.

Deliberative engagement provides an opportunity for the public to share and develop views with each other and directly with experts and decision-makers. Four workshops were run in consecutive weeks, enabling participants to build up rapport within their discussion groups as well as increasing their own knowledge of the outpatient system. This ensured that over the course of the four weeks, each group worked closely together to share and develop their increasingly informed views about the transformation of the outpatient system. NHS Sussex representatives were present at all four workshops and visited each discussion group to observe, but without contributing. The purpose of this was to ensure they did not influence the discussions but could observe feedback at first hand. They were also available to respond to questions in the main room.

Deliberative dialogue

There are currently three different types of deliberative engagement in the UK[11], "deliberative research", "deliberative decision-making" and "deliberative dialogue". The third type, "deliberative dialogue", aligns best with the format of the outpatient workshops. Participants and providers worked together, with some expert input from NHS Sussex. Participants had the opportunity to discuss viewpoints and agree on some recommendations and suggestions for improvement. Participants were also able to put their views and recommendations directly to decision-makers. Participants are also invited to hear the presentation of the findings and to comment on these before the findings are presented to NHS Sussex.

Principles of effective deliberative engagement in this project

Some key principles of deliberative engagement were demonstrated throughout the outpatient workshops, namely:

Makes a difference

Participants were encouraged to learn (as described above), to be heard and to engage with their discussion group. Participants were also offered the opportunity to put additional questions and comments into the chat function. HWBH kept in touch with all participants between each workshop and responded to any questions asked individually. In addition, HWBH presented the findings to participants and encouraged them to contribute comments on anything that was missing, so these could be incorporated into the final presentation HWBH gave to NHS Sussex.

Transparency

Participants were provided with support to ensure access to the workshops, different perspectives were heard and relevant information was given. It was recognised that these workshops were not face to face and may have limited access for some participants. However, an online format made it easier to reach participants across a wider geographic area (Sussex). HWBH ensured that either participants were confident with accessing online meetings (Zoom) or they were offered support through 1-2-1 training. As explained earlier, Healthwatch in Sussex recruited a

---

[11] According to the National Consumer Council (2008) *Deliberative public engagement: nine principles*, p.4.

participant group with a mixture of perspectives and NHS Sussex provided relevant information about the outpatient transformation.

Integrity
HWBH and NHS Sussex were transparent in explaining the reasons for the transformation, the objective of the workshops, and what could and couldn't be changed within the remit of the outpatient transformation.
HWBH proposed that the first workshop would give participants an opportunity to talk about their previous experience of the outpatient system (positive or negative) as well as to pose questions to NHS Sussex. This ensured that the following three workshops would focus on the proposed initiatives for the transformation and gauging participant feedback on these. These three workshops encouraged participants to look at the initiatives from the viewpoints of other patients, in addition to their own experiences.

Participant balance
HWBH ensured that participants came with a range of experiences of the outpatient system and presented with a range of different health needs.
Amongst the group, some people reflected on a positive experience of the outpatient system, while others had negative or mixed experiences. To ensure this balance, participants were recruited via various methods and HWBH carried out a robust screening process to ensure participants represented a mixed profile.

Publicity was sent via the respective Healthwatch mailing lists (Brighton & Hove, West Sussex and East Sussex), various community mailing lists, and via social media as well as targeted publicity to people who had participated in previous Healthwatch projects. Each hospital in Sussex was contacted with a poster to display in outpatient departments. Participants were recruited from a mixture of these publicity methods.

HWBH carried out a robust screening process to ensure participants were committed both to the educational aspects, as well as full involvement in the workshop discussions. We also wanted to avoid any automatic responses due to the £100 thank you reward that was offered in exchange for attending all four workshops. For applicants who showed an interest in being involved, HWBH sent out a set of screening questions which required

qualitative as well as quantitative responses, to ensure responses were genuine and not automatic (see Appendix A). These included asking about where the applicant had attended an outpatient appointment and a description of their experience, as well as contact details.

HWBH reviewed all screening questions to ensure a mixed representation of geographic location plus other considerations (see participant profile). A HWBH member of staff then phoned each applicant to explain about the workshops and to gauge their genuine interest in the project as well as reconfirming their availability to attend all four workshops. Applicants who successfully met these criteria were confirmed as participants in the project.

Respect
Everyone should be heard in the workshop and their views respected even where there is disagreement. HWBH set out some ground rules at the beginning of each workshop, regarding respect for other viewpoints, being mindful of not dominating the discussions and allowing others to contribute. The format of the outpatient workshops gave most of the time to smaller discussion groups. Being facilitated ensured that everyone was encouraged to speak, and time was managed to allow for this. Facilitators fed back to the main group afterwards, which also ensured all view points were heard, and note takers for each discussion group were asked to record each point even when made only by one participant.

Priority for participant discussions
As already discussed above, most of the time was given to participant discussions, note takers recorded these and facilitators managed and fed back to the main group. In addition, the main session was recorded so that the write-up afterwards, included any key points made. Participants were encouraged to make additional comments and questions in the chat function and these were also recorded.

Review and evaluation to improve practice
HWBH met with NHS Sussex on a weekly basis throughout the project. This included a pre-workshop preparation meeting and de-brief sessions after each workshop, providing an opportunity to discuss what had worked well and what could be improved for the next workshop. The last workshop

was left unplanned so that it could be shaped according to any gaps that were left unmet from the previous workshops. As a result, the last workshop was run in two halves, firstly asking participants for any further suggestions as to how to transform the outpatient system and secondly how they would suggest communicating the transformation to the wider public.

Participants are kept informed
HWBH stayed in touch with participants throughout the project. Weekly emails were sent in preparation for the following workshop, and in answer to any questions that were asked individually by participants. Reminders were also sent prior to each workshop including log-on details and the subject matter. As already discussed, several types of participant information was sent to everyone to help them prepare for each workshop. In August 2023, participants were invited to a presentation of the draft findings, two weeks before the main presentation of findings was given to NHS Sussex. This provided an opportunity for participants to respond to the presentation before it was finalised. Participant feedback was very useful, and suggestions were incorporated into the recommendations.

5. Participant Profile

HWBH aimed to recruit a diverse group of people, from across Sussex, who represented a range of ages, geographic location (across Sussex), sexual identity, and ethnic diversity. NHS Sussex also requested that representation included people caring for others who had received outpatient care. We also looked to recruit participants with a range of health needs, and who had experienced the outpatient system through a variety of departmental specialties.

The 31 participants who attended three or more workshops were fairly evenly spread geographically between residents from Brighton & Hove (11), West Sussex (12) and East Sussex (8).

Geographical Spread

West Sussex ■ East Sussex ■ Brighton & Hove
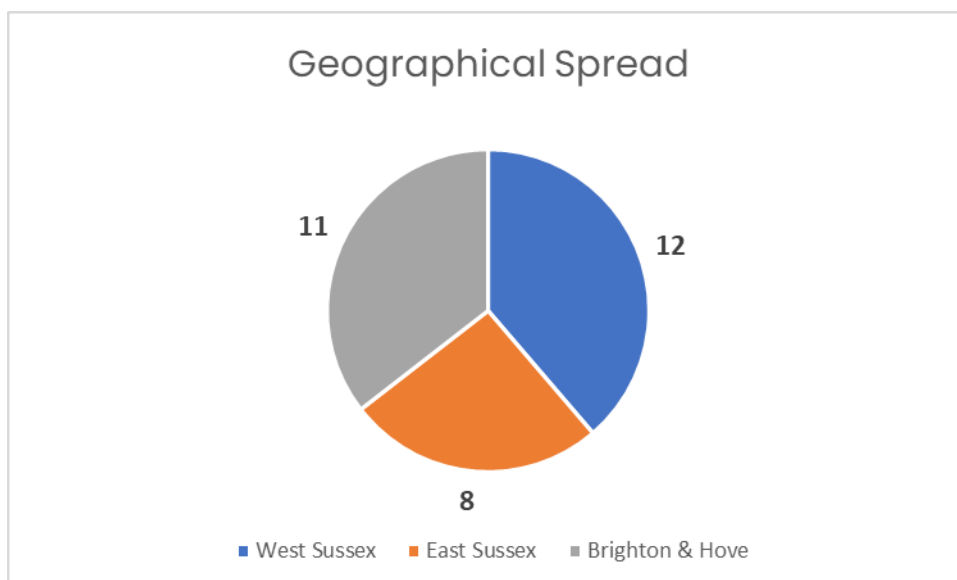
Most of our participants (20) had long-term conditions (LTCs). Seven participants did not have an LTC, and four participants did not say.

Of those participants who defined themselves as having an LTC, two people did not specify what LTC they had.

From the remaining 18 people, 16 had a physical impairment, four a sensory impairment and two a mental health condition. Three participants presented with *more than one* LTC.

Therefore, the graph below shows a total of 22 LTCs derived from 18 people who specified their LTC.

Participant long-term conditions

mental health condition, 2

Sensory impairment, 4

Physical impairment, 16
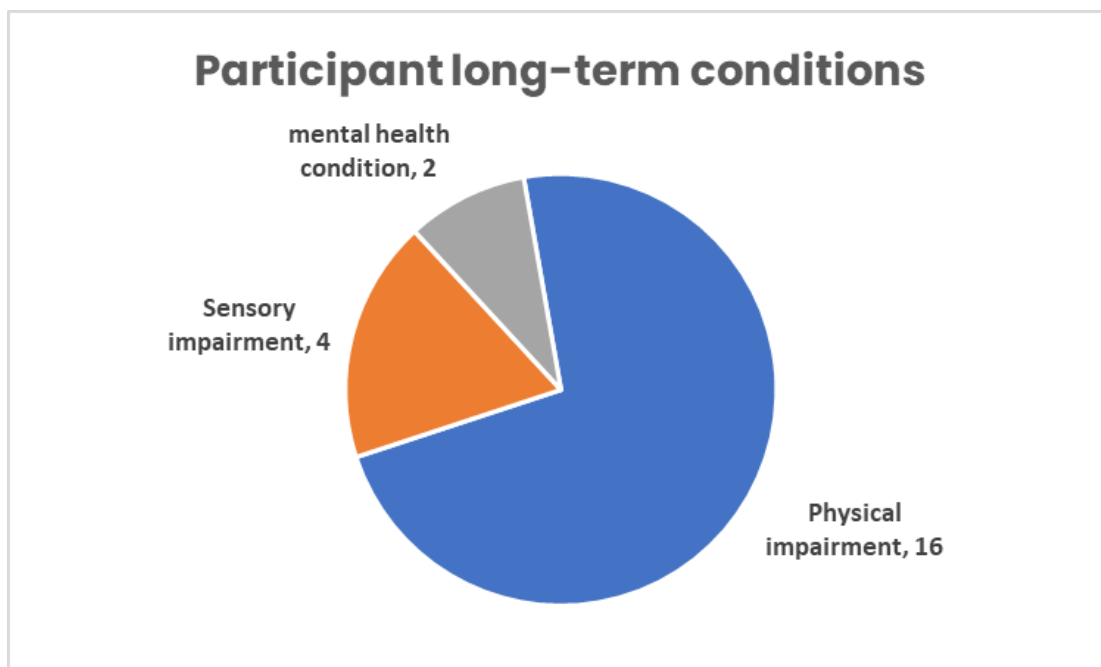
Participants suffered from a range of health conditions, some of which related to their outpatient experience. These included back issues; arthritis; hearing issues, language issues, asthma and being registered blind. Also, cancer, brain damage, lack of balance, coronary/heart problems, and general pain.

Participant experience of the outpatient system was also mixed. Many participants had attended an outpatient appointment (27) and 8 were waiting for an appointment (some had attended one appointment and were waiting for another).

Of the experience so far (either waiting for or attended) 11 participants had a positive experience, 14 had a mixed experience, 2 a negative experience and 3 participants said their experience was "neutral". One person was very early in the process and did not have any comments to share about their experience.

Previous experience of Outpatient appointments

Neutral, 3
Not yet taken place, 1
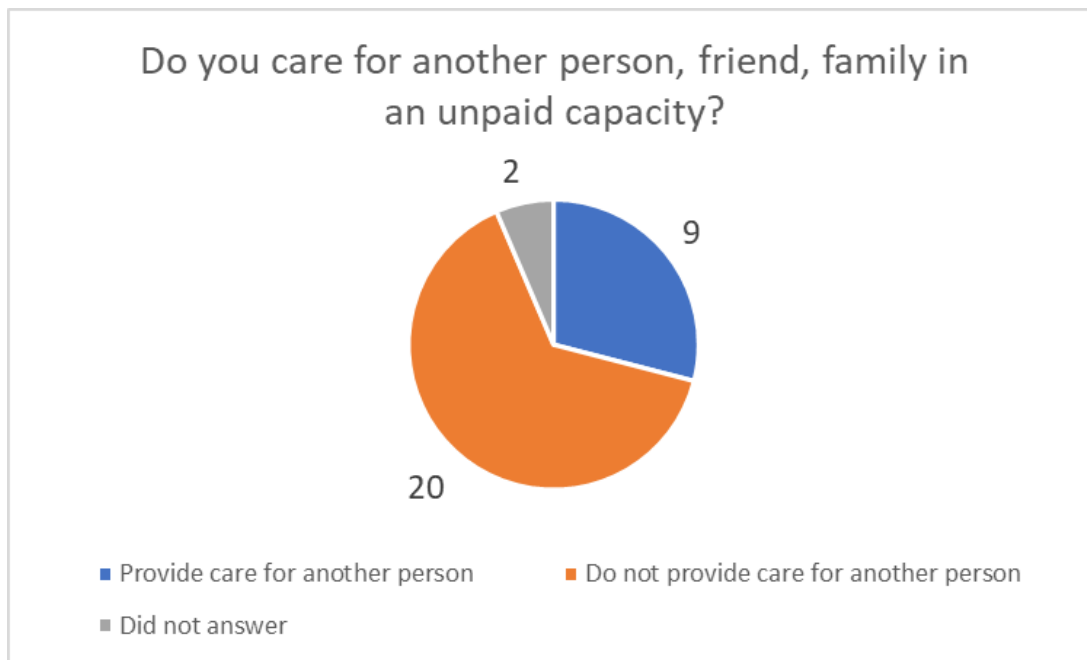Positive, 11
Negative, 2
Mixed, 14
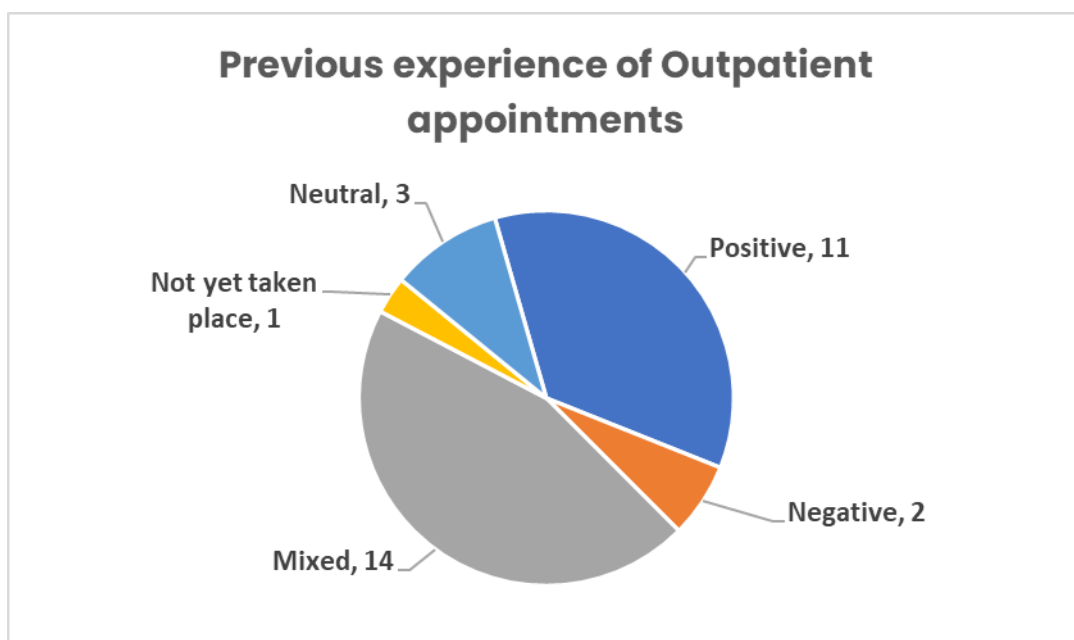
We asked participants if the appointment was for themselves or for a person they cared for. This was asked of all participants, whether they had attended, or were waiting for, the appointment.
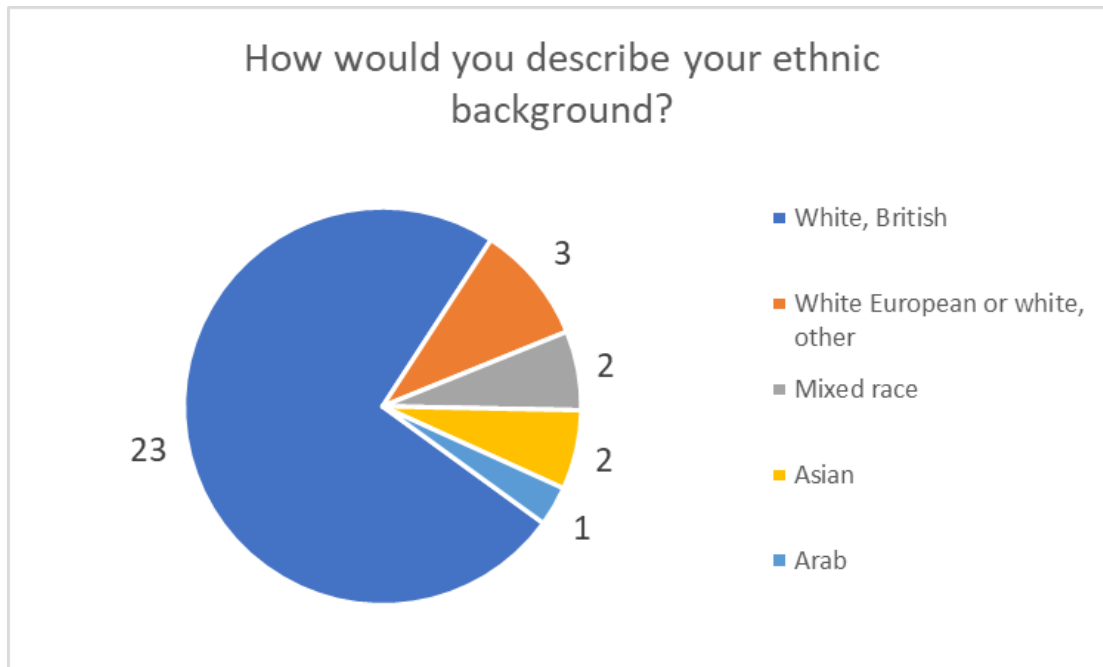
Respondents identified that most appointments were for themselves (25). One person had experience of an appointment that was for a family member they cared for and five people had experience of both types of appointments. Therefore 30 people had experience of appointments for themselves and six people had experience of appointments for someone they cared for, in each case this was for a family member.
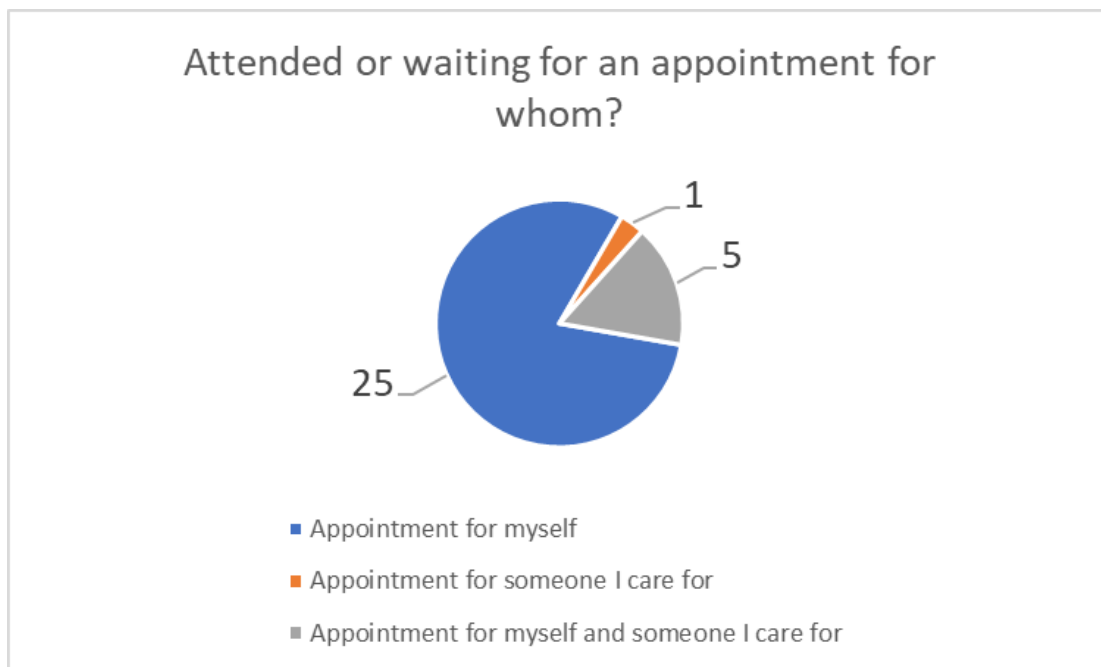
We also asked participants if they were responsible for "caring for another person, family member or friend". In addition to the six participants above who had experience of an appointment related to a family member they cared for, a further 3 participants identified themselves as being in this category. In total therefore 9 participants identified themselves as "caring for another person, family member or friend".

Do you care for another person, friend, family in an unpaid capacity?

- ■ Provide care for another person
- ■ Do not provide care for another person
- ■ Did not answer

While most participants (23) were "white, British", three participants were "white, European", or "white, other" and five were non-white. Two participants were "mixed race", two were "Asian" and one identified as "Arab".

How would you describe your ethnic background?

- White, British: 23
- White European or white, other: 3
- Mixed race: 2
- Asian: 2
- Arab: 1

Participant ages ranged from 22 to 84 with 64 years being the average age. Most participants were straight; three identified as either Asexual, Pansexual or as a Gay man.

6. Pre-workshop Information

As part of the deliberative engagement process, all participants were sent reading material prior to the workshops. The information was prepared by NHS Sussex, in discussion with HWBH. Some of the background as to why Outpatient services were being transformed was explained.

It included a brief description of the four initiatives that were being proposed to enable this transformation, namely Advice & Guidance (A&G); Utilising System Capacity (Patient Choice); Patient Initiated follow-up (PIFU); and Reducing Did Not Attends (DNAs).

The information also included NHS Sussex's aims for the workshops, namely to:
1. Gain an understanding of what is important for patients within this system,
2. Discuss patient views on the four initiatives;
3. Embed these views into the transformation programme going forward; and
4. Discuss options for ongoing patient engagement.

Participants were asked to read the material prior to the first workshop so that they were informed and ready to participate in group discussions.

To view the workshop information shared with participants, please visit participant information.

> **The following write-up of findings includes many quotes directly contributed by workshop participants that help illustrate the key themes. To avoid repetition, not all quotes have been included. However, these are available on request.**

7. Workshop 1: Participant experiences of the outpatient system and suggestions for improvement

The first workshop gave participants a chance to talk about their experience of the outpatient system so far. Participants were split into four discussion groups. A facilitator for each group asked participants to talk about their experiences and answer the question, *"What are the two things the NHS could have done to improve your experience?"*

Findings from the discussion groups

Themes were similar across all four discussion groups and have therefore been collated below.

1. Participants acknowledged that problems were usually associated with the system and not with individuals.
2. Participants expressed frustration with booking and/or rearranging appointments, waiting times for referrals and patient transport issues that caused late arrival to appointments.
3. Participants explained the frustration of not being updated while waiting (often weeks or months) for a referral and the sometimes unkind responses to their request for an update from booking staff.
4. Treatment of the individual was raised, particularly when a patient needed additional support, but also participants spoke about there not being enough time for doctors and consultants to understand the full patient history before treating the condition.

In detail:

Positive experience

Participants were keen to share some positive experiences. On the whole, people agreed that the problems were usually due to the systems and process rather than individual health professionals. The following quotes are representative of comments made by several participants.

"On the whole my experience has been brilliant."

"It is not individuals; it is the system."

Patient transport delays

Several participants shared their frustration about being late for their appointment due to the patient transport being delayed.

"I had an appointment at 9.30 and the transport didn't come until 10.30."

"There is a problem that patients don't come on time…I am in a wheelchair and rely on transport."

Delays/Waiting times

Patients shared their frustration over delays and waiting times. Patients shared their experiences of waiting a long time for a referral to come through, and others shared experiences of arriving for an appointment and being made to wait a long time. Also, participants shared their frustration of seeing other patients arrive late for appointments. One participant shared a positive experience.

"Not heard anything, told it would be three months but nothing, they make promises but don't do it."

"I have learned I won't be seen on time – so I take a packed lunch."

"I have been notified of results months and months later."

"If patients don't turn up within 10 minutes of their appointment they should be asked to wait until the end of the surgery."

"I have had a really good experience with quick turnaround on referral appointments coming through."

Understanding individual needs

Participants discussed experiences that could have been improved by their individual needs being considered. There was a general discussion about other groups to consider, for example, school children. Other participants questioned whether the NHS could afford to cater for individual needs. Participants felt that knowledge of the patient's history

was particularly important where the patient had more than one long-term condition.

"The patient shouldn't have to go through the issue again and again."

"When attending a gynaecological issue, I was allocated a male consultant, which I didn't want – they arranged for me to see a woman – two weeks later."

"I cannot see how the NHS would embrace the idea of 'personalization' of appointments…already stretched services."

"Extra time in appointments for people who are hard of hearing, people with learning difficulties or who have other extra requirements."

Some participants shared their experience of needing their carer involved and described the importance of incorporating advocacy into the system for those needing it.

"I have a hidden heart condition and my partner is my carer. They were told to sit outside. I am useless without her – she is my memory."

"Can we give people attending outpatient appointments more advocacy?"

"As an interpreter, I've had the common experience of a lack of communication with people who don't speak English – the system isn't accessible for these patients."

Difficulties with booking appointments
Patients shared their experiences of finding it difficult to get through to the booking line and of leaving messages and not receiving any response. Others talked about their frustration of having appointments cancelled. One participant shared a positive experience of having appointments rearranged closer to his wife's.

"In the last six months my appointments have been booked, cancelled, and rebooked."

"The secretary doesn't answer the phone and there isn't anyone to contact – it's very frustrating when you have a long term condition."

"I have had to ring four times before to write down an email address as the voicemail is so fast!"

"When they saw my wife's appointment on the day, they moved my one closer to hers which was positive."

Communication suggestions

Participants agreed that patients should be asked how they want to be communicated with (telephone, email, letter) and this should be noted down on their patient record. Often a phone call is more suitable so that the patient can ask questions and clarify information that would otherwise be ambiguous in a letter.

"There needs to be a clear list of the various ways the patient wants to be communicated with, e.g. phone, email etc. Some patients may not have a smartphone."

"Text reminders are very useful but can be confusing if you get multiple ones for different things."

"Ability of some patients to provide appropriate evidence e.g. photos for sharing with specialist."

Participants had suggestions of how to communicate better with patients, including having a system for offering cancelled appointments.

"Can they write to people and ask whether they can make appointments at short notice, to make use of cancellations?"

"Having cancelled my appointment, they still called on the day of the original appointment and I was almost accused of lying."

Travelling for appointments

Participants talked about their experiences of being offered appointments that involved travelling outside of their local area, and their frustration when the longer journey is met with delays in the hospital. There was shared experience amongst participants of being offered appointments across two different hospitals.

"Being pushed out of the county is hard, when you don't have a car."

"It really is important to use local facilities as much as possible, considering the circumstances of the patient."

"Travelling to London for blood tests rather than the hospital providing treatment – making a two hour journey and then waiting for the phlebotomy appointment."

"I had a cancer diagnosis and was given three follow-up appointments spread across two different hospitals."

"I am the sole carer for my mother who lives in a rural area. Travelling is difficult as my mother is in a wheelchair."

"I should have a check-up every year, but it took me three years to get it. Seeing a consultant in the community, at a GP practice would save on the travelling."

Convoluted referrals and GP issues

Participants reflected their frustrations at referrals that had to be re-routed via their GP and seemed to take longer as a result. Participants also shared experiences with miscommunication between their GP and the hospital department they were referred to.

"My optician is not able to refer me to hospital, so have to go back to my GP to make the referral."

"My daughter moved out of the area, she kept getting re-referrals – eventually she was sent back to the GP to get referred on –very frustrating!"

"My GP expected me to arrange my own referral to an audiologist – it was difficult to communicate directly with my GP and I have had no communication for the past six months."

"The Radiographer was unable to proceed with the scan as he had not received my notes from the GP."

Remote vs. Face-to-Face appointments

Participants discussed some benefits to virtual appointments, making the case for saving the patient time and money in travelling to hospital. However, there was an acknowledgement that virtual appointments do not suit everyone. Some participants shared negative experiences of remote appointments where the timing was unexpected, or internet issues caused the patient to miss some of their appointment.

"More remote consultations, saves slots at the hospital."

"Trying to book online appointments is very frustrating."

"They rang me for a phone appointment an hour early – I could have missed it!"

"A remote consultation with a specialist, could have saved travel costs and parking at Hospital. I was not given that option."

"Video link dropped out - I did not receive a call back and it was assumed that I had terminated the call which was not true. I had to go back to my GP and start the process again."

"There is a mixed ability world for information technology."

Environmental issues

While these were acknowledged to be outside of the remit of the outpatient Transformation Team, participants shared some observations regarding the hospital buildings and environment.

"Poor signage in the outpatient department, especially for those partially sighted."

"Bring back the reading materials that were removed during Covid."

"I was told to go upstairs – there was no lift and I had two sticks and a 'boot' on my broken foot!"

"I was late for an appointment because only one of the five lifts was working."

"There was a board with times, but it was all out of date."

Staff training

Participants reflected on training requirements for staff, for example, in dealing with patients with extra needs. Some participants shared negative experiences of speaking to reception staff.

"There was no one there when I arrived or any reception – when I found someone I was told 'we are not expecting you' so I showed them the appointment letter!"

"All medical staff need to know and be able to guide blind people properly."

"Reception staff attitude can be poor – not good when people are not well"

"Do reception staff receive any customer service training? Sometimes they don't even acknowledge you!"

"A consultant for my husband, had not read the files on his dementia and was very arrogant in updating me on his condition."

"After trying to get an update on a referral for a long term condition, I was told to stop contacting the hospital unless I was an emergency cancer referral, as they had a long waiting list. The experience was disempowering."

Allow more time for doctors to understand the patient's history
Participants discussed their general frustration at the lack of time given for doctors/consultants' appointments. Participants felt there was not enough emphasis or time given for the doctor to read a patient's notes and understand the full context of their condition.

"We need to give clinicians time to know about their patients – they don't even know why you are there!"

"Need to have more time for clinicians to be curious – to progress things that aren't a nice clear picture. People end up feeling dismissed."

"Staff are in distress, and this puts patients off contacting them."

"There's a big issue with patients not being heard – a missed cancer led to [the patient] needing to seek treatment elsewhere!"

8. Workshop 2: Advice and Guidance (A&G)

> Summary note on Advice and Guidance: This enables GPs to seek advice and guidance from consultants about diagnosis and treatment, with the potential that the patient need not visit the hospital but be treated in the local community.

Participant information

Using the deliberative engagement method, participants were fully informed about A&G before they were asked to discuss the initiative in their workshop groups.

Prior to the workshop, all participants were sent information which described the initiative with some examples of how it would work. It included a video of consultants and GPs explaining the benefits of the system from their viewpoint. The information also included how the initiative has been piloted in parts of Sussex and future plans.

Participants were also sent a scenario that gave an example of a patient's journey in which the A&G initiative was used. As with Workshop 1, participants were split into four groups, two of these received one type of scenario (1A) and the other two groups received a different scenario (1B). Participants were asked to read the scenario in advance in preparation for discussion within the workshop.

At the beginning of the workshop, NHS Sussex gave a presentation which further described the A&G initiative, including an example of where it might benefit the patient journey.

To read the full workshop information shared with participants including A&G information, scenarios 1A and 1B and the NHS Sussex presentation, please visit participant information.

Findings from the discussion groups

Each of the four groups were tasked with discussing the scenario they had been sent and answering a range of questions, namely:

- *What works well in the scenario given?*
- *What could work better?*
- *What support might be needed for the scenario to work effectively?*
- *Can you see this causing any barriers for some patients?*

As themes were similar across all four groups, regardless of the scenario being discussed, the responses have been collated and grouped accordingly.

1. Participants felt that direct communication between GPs and consultant could benefit the patient, as they were likely to receive answers quicker via their GP rather than waiting for an appointment with the specialist.
2. However, participants felt that this initiative may not work for some patients or for certain conditions.
3. Patient communication was seen as a priority for this initiative to be really successful.

In detail:

What works well?

Speed of process

Participants agreed that the A&G system seemed logical and could work well. It could potentially speed up the process of diagnosis, with less time to worry or be in pain, as well as avoid unnecessary hospital appointments.

"By going straight to the expert knowledge, it cuts out the time to suffer pain."

"It is re-assuring to have secondary follow-up (where appropriate) to ensure the best outcome."

"A clear pathway for the process."

Improves GP knowledge

Participants discussed the impact of A&G on the GP. It was felt that closer communication with the consultants, might lead to increased knowledge and awareness of some conditions.

"Over time it will improve the knowledge base of the GP."

"I like the idea of the GP talking to a specialist."

What could work better? What support might be needed for it to work effectively?

Only for certain conditions

Participants felt A&G would work better for some conditions than others. They questioned whether a consultant could advise remotely on brain or heart conditions, for example. Also, that some subtleties might be missed. Some participants suggested an alternative to A&G could be care in the community.

"Sounds good for this scenario with the dermatologist, but not if you had a heart or chest condition."

"You can't look at a patient's brain, you can't put that in an email."

"Concerned in the scenario that they were prescribed two medications which could be confusing."

"Photos are only so good."

"When you see the patient, you can diagnose by the way they appear. They must be seen."

Patient involvement and communication

Participants called for more patient involvement in the system. If the GP is receiving advice & guidance (through the A&G initiative), participants felt the patient should receive the advice at the same time. Participants suggested an NHS app to track the development of the process so that patients can keep updated on where they are in the system.

Follow-up referrals need to be sensitive and appropriate for the issue being addressed e.g. the scenario given was about a referral for weight-management and could be upsetting for the patient if the initial appointment was for heart palpitations. With patient involvement in mind, they should be given advice on self-help and available support, as well as clear information on actual next steps including realistic timelines.

"The flowchart is great for professionals but needs to include the patient."

"A clear explanation [to the patient] of A&G needs to be built into the first consultation."

"Whenever you see a consultant, the GP gets a letter. Why not send the letter to the patient and copy in the GP?"

Joined up working between departments

Where two or more specialities are involved, participants felt it was really important to ensure all communication was joined up, and that the GP and patient were both kept informed.

"If the matter is referred on to another specialty, there needs to be a mechanism to co-ordinate different services."

"If a patient has different referrals ongoing, would the link between GP and specialist function work well?"

Negative effect on GP status

Some participants felt that consistent or repeated referrals to a specialist might reduce the patient's trust in their GP's ability. Some people felt A&G might create more work for the GP, due to the time taken to communicate with the consultant.

"What if the initial treatment suggested by the GP is then advised not to be right by the consultant – this might destroy trust in the GP – especially if they had rushed to treatment before a response from the consultant was received."

"The additional load on GPs! – they are overloaded already."

"Will take time for GPs to get used to this, they will need time and really depends on what the consultant wants."

"Why would they prescribe the treatment if they were not certain?"

Barriers for some patients

Participants felt that older people, and those without English as a first language would find it difficult to engage with this process. The system should be adaptable for people with neurodiversity, learning disabilities, carers and patients with dementia. This would help ensure these patients fully understood what was happening and how long it might take for the GP to receive the advice. One breakout group discussed specific timings of 48 hours in an urgent case and up to one week in other cases.

"When you get older you may have many conditions."

"Need to find ways to communicate with patients who use other languages. Relying on relatives or carers who know English may not be ideal because of the technical terms used in medicine. We need interpreters."

"The role of the family is important [especially for those cared for]. Consultants need to know if the patient will have someone with them."

9. Workshop 2: Utilising System Capacity (Patient Choice)

Summary note on Utilising System Capacity (Patient Choice). This is where an alternative referral location could be offered to patients, which may enable them to see a consultant quicker. However, the provider offered may be in a variety of locations, sometimes outside of the local area.

Participant information

Using the same deliberative engagement method, participants were given three pieces of information before and within the workshop about PATIENT CHOICE, namely:

- Before the workshop, patients were sent the following:
    - Participant information describing the initiative (all participants)
    - A scenario describing a patient's journey in which Patient Choice was used. Two groups received one type of scenario (2A), and the other groups received a different scenario (2B).

- Within the workshop:
    - A presentation by NHS Sussex was given on the benefits of Patient Choice and some additional patient resources.

To read the full workshop information shared with participants including Patient Choice information, scenarios 2A and 2B and the NHS Sussex presentation, please visit participant information.

Findings from the discussion groups

Each of the four groups were tasked with discussing the scenario they had been sent and answering the following questions:

- What works well in the scenario given?
- What could work better?
- What support might be needed for the scenario to work effectively?
- Can you see this causing any barriers for some patients?

As themes were similar across all four groups, regardless of the scenario being discussed, the responses have been collated and grouped according to theme.

> 1. Participants felt this initiative could work well and enabled patient choice.
> 2. However, there was a risk of lack of continuity between local services and the alternative location offered.
> 3. For patients with mobility issues and/or without their own transport, the alternative location could be difficult to access.

In detail:

What works well?
Process works well
Participants said that generally the process made sense, and some participants had good experience of using this system in the past. Some patients are happy to go a longer distance to receive healthcare earlier. Participants hoped the initiative would free up spaces locally.

"The process seemed to work well in the scenario, especially for patients that were able to drive. It has worked well for me [in the past]."

"I can drive and would be happy to go a reasonable distance if offered."

"Where possible, having a quicker appointment is going to be more relaxing for the patient – less waiting time for a result."

"I would travel further because I can, I'd travel to the moon to get quicker treatment."

"Really good [initiative] in that if people travel elsewhere, it will reduce pressure on local hospitals."

Element of choice is important
Participants felt that having patient choice in their healthcare was valuable, even if the options were not always suitable. Some participants asked about the option of private care.

"It really comes down to personal choice, choice is important and based on the person's ability to get there."

"Even if it's not a good choice, at least the patient is given the choice."

"Is there another choice - a third option? For example, during Covid I was referred to a private provider for surgery."

What could work better? What support might be needed for it to work effectively?

Shorter waiting times in the first place
Participants felt that if the system worked well and waiting lists were shorter, the initiative wouldn't be required as every patient could be seen locally.

"There is supposed to be equality of resources across the country so why would waiting lists vary so much."

"In the end we need more doctors to be trained and retained."

"Could not the specialist have a room in the GP surgery to see the patients there."

Sharing paperwork across Trusts needs improving
Participants felt there needed to be better joined-up working between hospitals across the county and the UK and that this would ensure Patient Choice could occur effectively.

"On holiday my heart stopped so I went to another hospital (in the UK) and they said, 'go back home to Worthing, take this paperwork with you, scan it and send it to your consultant' – how archaic!"

"If I was not able to get all my medical records at another Trust, they may not know the full story."

More available patient transport

Participants indicated that there was not enough communication around patient transport and who it was available for. One of the participants was autistic and was unaware that this option was available to them.

"Would work if you had [effective] patient transport. That would really make it 'patient choice'."

"Better communication around patient transport and who it is available for."

"I see patients waiting for such a long time for transport."

"[Patient transport] may be really important for the visually impaired."

Consideration for time and cost of travel

For Patient Choice to work effectively, thought should be given to the travel time and cost of travelling to the alternative location. For example, if a patient is offered an appointment that requires an hour's travel time, late morning onwards is likely to be more practical than offering 9am. Equally, offering an alternative appointment in London is costly, particularly if travel needed to start during commuter time. Consideration should be given for a later appointment and in some case, support with travel expenses could be offered.

"Time of day of appointments is a key issue. Might be able to travel if appointment times are later. It can cost a fortune to get to London for an early appointment. Some may not be able to afford to travel. There is some help for those on benefits but others who are near the breadline often do not qualify."

"Time off work for carers is often a problem."

"Travelling options need to be easy and timing of appointments is important."

"Some hospitals reimburse transport costs."

Continuity of care

Participants were interested to know if there would be continuity of care between the local and out-of-area NHS services and sites. Participants asked how patient information would be shared. Participants were concerned about where the responsibility lay for care – locally or with the out-of-area provider.

"If my child went elsewhere (another hospital) who is responsible / accountable for what? – if issues arise these shouldn't just be pushed down the road."

"Whose responsibility is it to inform the patient of patient choice?"

"The hospital you go to needs proper access to medical records that your GP has e.g. complications [in the condition]."

Obligation to attend alternative offered

Participants asked if once a patient had committed to an appointment further away, would they remain on the list locally, or be obliged to attend all follow-up appointments at the alternative location, further away.

"Interesting to know if patient would have to return to the same [alternative] place, [for any follow-up appointments]."

"For most people distance is no problem, but would follow-up appointments still be out of the area? It might be OK to go a long way once, but will patients want to commit to going a long way on multiple occasions?"

Practicalities of an alternative hospital and information needed

Participants spoke about knowledge of the practical aspects of the alternative location and how this might affect their decision to take up the offer of somewhere new.

"It is important to know in advance what the parking is like or is it near a station."

"As a disabled person with specialist care, for a variety of different medical conditions, I would need advice about which methods of travel would be best for me."

"You could add a patient's travelling ability to their record, so knowing who would be more likely to take up the offer."

"I cannot drive. I have had to go from Eastbourne to Bexhill or Brighton. There is a lack of information on what is or will be provided."

Information needed to support a patient in making the decision to accept the alternative location

In order to decide whether to accept an alternative location for treatment, participants felt there was a need for further information than seemed to be currently available to patients. Participants spoke about the need for clarity on a typical wait time for the appointment offered, as well as minimum and maximum wait times, to inform appropriate decision-making. Participants also discussed the need for support in the meantime, while a patient is waiting for the appointment, to deal with current symptoms (pain management) or the impact on mental health of waiting, for example, signposting to local support groups. Participants also realised that some patients would need to know they had a friend or family member available to accompany them to the appointment.

"[Some patients may need to know there is] the possibility of someone to accompany them."

"It can be difficult to make a decision as to how long a wait is acceptable as the patient may not know how serious a symptom is."

"If there was a National List that indicates the availability and waiting times for various hospitals and their treatments, this would help when making a decision re: travelling further."

"All information needs to be accessible e.g. Easy Read."

"It depends on a person's mental health – patients need clarity on the differences of waiting times between different hospitals – in the example both seem a long time to wait – even the shortest wait might be too long – might need to assess how bad the wait would be on the patients mental health."

"I would want more information on performance than is on the NHS website – more on consultant outcomes."

Robust Infrastructure is required

Participants were concerned with communication and the link between the GP and the specialist, and this would be exacerbated if different locations are being offered. Participants were concerned whether their GP would have all the up-to-date information related to different services (e.g. performance) and how much would be left to the patient themselves to find out and interpret. Some participants were concerned with GPs being over-worked due to lack of support staff.

"Would GPs be aware of the various waiting times at different hospitals in order to be able to advise the patient?"

"I don't know how clued-up GPs are about the options and the other support available e.g., the Tinnitus Society – do the GPs have a list of other organisations so that they could refer people?"

"There are not enough admin staff which means doctors and nurses end up doing the admin which is very expensive. The underlying infrastructure is often not there, and this is often why these initiatives fail and this creates tension for staff."

Participants also felt communication with the booking team needed to be easier, quicker, and more direct, to ensure flexibility with the patient and maximising the opportunity to re-use appointments cancelled by others as a matter of routine.

"There needs to be an easy way to communicate with the booking team, to sort out issues with travelling to appointments. Hospitals need to be flexible to accommodate patients travelling distances."

"Offering patients appointments where there has been a cancellation should be the default. But I don't think every patient is asked if they will take a cancellation, should such an appointment become available."

"Not worked for me in the past, I seemed to be passed from pillar to post – and I felt I was going round in circles."

"You need one point of contact."

Barriers for some patients

Barrier for certain groups of people

Participants highlighted that offering an alternative location for an appointment might not be suitable for certain groups of people. For example, patients for whom English is not their first language, navigating their way through an unfamiliar location and hospital may be more difficult. For older people and those who are reliant on others to accompany them, the alternative location must be feasible for their carer.

"Elderly people could find it challenging to travel further."

"What about those with caring responsibilities, people who have children, people who are disabled may not use it."

"It can be tricky for patients in care homes to access hospital care."

"I would find the whole process very worrying, and I would be very anxious as I am Autistic."

Condition-based

Participants discussed that the severity or type of condition could be a barrier to accepting an alternative location.

"Depends on the severity of the condition."

"Really depends on the severity of the condition and how long they may have to be away from relatives."

People without transport

Participants discussed that being reliant on others and/or having no transport of their own, could be a barrier for some patients.

"I live in Chichester. I had an appointment in Cosham [Portsmouth]. Husband could not drive me on this occasion. So went by bus. The route is ok but getting to the bus stop is the problem. So that can stop me accessing public transport."

"Concern about the NHS becoming a 2 or 3 tier system. Not everyone has a choice because not everyone has the wherewithal to travel."

"It might not work so well for lower income groups having to access public transport."

"People might not be near public transport – I have a local station but only one bus an hour – it could be bus, train and bus to get to a hospital."

10. Workshop 3: Patient initiated Follow-up (PIFU)

> Summary note on Patient initiated follow-up (PIFU): After the initial consultant appointment, usually a patient would be given a follow-up appointment on a set date and time. Instead, PIFU gives the responsibility of follow-up to the patient, where they decide if and when they need an appointment. They are then expected to proactively telephone (using a number provided in advance) and make their own booking for a follow up appointment.

Participant information

Using the deliberative engagement method that was used for previous workshops, participants were given information before and during the workshop about PIFU.

All participants were sent some general information on PIFU to read before the workshop. During the workshop, before group discussions, participants were given a presentation by NHS Sussex on PIFU.

Participants were divided into the same four discussion groups as previous workshops. Two of these groups were given a sample patient letter or a sample patient leaflet respectively. The letter and leaflet advised an anonymous patient that they were being offered PIFU. The information explained what PIFU was and how the patient could arrange a PIFU appointment.

Both of these groups were asked to read through the sample letter/leaflet and consider the following questions in their discussion group:

- Is the information clear, complete, and concise?
- Would you feel confident that you understood what was required of you as the patient after being placed on a PIFU pathway based on this information?
- Can you see this causing any barriers for particular groups of people?

The remaining two discussion groups were asked to discuss PIFU on the basis of the presentation by NHS Sussex. These two groups were asked to think about the following in their discussion:

- What are your immediate thoughts on PIFU, positive/negative?
- Does this cause any barriers for particular groups of people?
- What additional support/resource would people need (if any)?

To read the full workshop information shared with participants including PIFU information, PIFU sample letter and sample leaflet and the NHS Sussex presentation, please visit participant information.

Findings from the discussion groups

PIFU – a good idea?
Themes were similar across all groups, regardless of the information given. PIFU was felt to be a good initiative and in theory the process could be a simple, direct way of patients taking control of their own care. However, some patients would need additional support to ensure they knew when to follow-up and there would be certain patients that would be unsuitable for PIFU altogether.

Patient information
For the participants who received a sample patient letter or leaflet, they felt that visual aids and a verbal explanation should accompany the written information to increase accessibility and allow the patient to clarify anything they have not understood with the health professional.

In detail:

What works well?

Information is comprehensive and process can work well
Participants felt this process should work well. The information provided (either in letter or leaflet format) was comprehensive and contained all the information required.

"Provided the criteria for PIFU, not overlong and happy to accept one."

"Not all the information is needed, but overkill is better than underkill. You need to tell the patient about PIFU but a year later you could cut it short as more people will know about PIFU."

"At the end of my last outpatient appointment I was given the letter and it was explained to me what grounds I should visit. Excellent, terrific! I had a check-up that I would usually wait 2-3 hours to see an ENT specialist for. Now I can phone up and get direct to the ENT. This direct contact is valid for 12 months and saves me from waiting in A&E."

"It is quite informative and might answer peoples' questions."

Involves patient in their own care
Participants felt that PIFU was a good way of involving patients in their own care and could be quite simple for the patient to initiate.

"In straightforward cases it puts the care in the patient's hands."

"It is important the patient feels involved – that they are not 'just a number.'"

"I was given a card by my orthopaedic consultant, so I knew how to get in touch if I needed to."

What could be improved? What support would the patient need to access this initiative?

More concise information

Some participants felt that the information given in the letter/leaflet was too complicated, and the language used was overly formal.

"The letter should be simplified."

"The term 'Hospital records' is very bureaucratic."

"The communication should be in plain English."

Patient information should be accompanied by a verbal explanation

Participants felt that anything written should be accompanied by a verbal explanation from the doctor/clinician, to allow the patient to clarify and ask questions.

"Need a conversation with a doctor to show you're on a PIFU pathway."

"The letter is very top heavy and needs that introduction from the clinician."

"It would be good if the letter was explained at the consultation."

"I had to read it 3 times to understand it. The clinician would make it clearer."

Multiple forms of patient information made available

Participants felt that multiple types of patient information would be more effective than a one-size-fits all format. Participants suggested there should be accessible formats available; and that additional information should be available about the process. Participants also felt that it would be useful for the information to be tailored to the specific service the patient is accessing.

"The information should be provided alongside a leaflet saying what PIFU is."

"…and in a range of formats like Easy Read."

"It should be possible to customise the information in the letter – and use other forms to communicate the information – we are in a multi format world."

"People need to know more about trials being run currently, where are they? And what specialties are being trialled?"

Robust Infrastructure is needed

Participants agreed that PIFU would only work if the correct infrastructure was in place. Participants were concerned about getting through a busy telephone system, not being called back, and if they did get through, participants were concerned they would not get an available appointment, and quickly if this was necessary. Online systems could help if they operated efficiently. Some participants had previous experience of the system not working and shared this in their group. Another participant had knowledge of other health and care transformations and felt these should all be joined up.

"My main concern from the letter is, am I able to contact the person I want by telephone? and not be put on hold or not rung back when they say they will."

"My personal experience of being offered a similar service didn't work. After several months (of being pain-free), the pain then returned. I went all around the houses to find someone, only to be told to go back to my GP for a new referral. Had I known this, I'd have contacted the follow-up

service several months ago. I wasted time when I could have been on the waiting list."

"For this to work, you need to have a quick response, e.g., if someone's condition flares up, then the response needs to be quick (not an appointment in three months for example)."

"Seems to be some sort of communication breakdown with the NHS App." *This participant was asked to use it for a referral but there was no information on it.*

"What about a system that works like choosing a supermarket delivery slot – an online system?"

Support for patients to know when to call

Participants discussed that some people would be unsure when to make a follow-up as they might not recognise the symptoms. Others might not use the follow-up system as they would not want to burden the health services, particularly considering the messaging around the COVID pandemic about staying away from the health services, unless absolutely urgent.

Participants asked how patients would be supported to make the decision if they are in doubt and wondered if there was a risk that this might lead to issues getting worse if people prevaricate.

"What about older people? How are we supposed to distinguish between an issue related to a medical concern or one that's just a part of getting older?"

"People are very aware of how busy the NHS is so may not want to add to pressure."

"Presents a huge educational problem that will need a multi-agency national approach to encourage people to call for an appointment."

"Will there be a system in place to ensure that those who don't follow-up themselves, are not forgotten? Assuming not as it would be counter intuitive from an admin perspective."

Patient choice and involvement of informal carers (friends and family members)

Participants felt strongly that it should be the patient's choice to go onto PIFU or not. For some patients, the conversation about whether PIFU is appropriate needs to be discussed with others who care for them e.g., informal carers such as friends and family members. A vulnerable patient may accept this initiative without fully understanding what it involves, especially when they are reliant on someone else booking appointments for them.

"It is not just patients but people who support them, that might say that it's not suitable."

"All very dependent on the patient's problems and why they are under a consultant."

"Patients should get a choice of going on the pathway or not."

"As a person with multiple mental health issues I find the PIFU concept quite intimidating; having to manage it on my own terrifying and overwhelming. I would need assistance from my carer (mother) to use this."

Barriers for certain groups

Participants discussed that even if the information was explained clearly and provided in accessible formats, and additional support was offered, there would be some people for whom PIFU would not be suitable. These could include some (though not all) elderly people and those with sensory needs, people who do not speak English as a first language, or who have reading and learning difficulties. Also, those that are not confident enough to be proactive or ask for help when needed, and those that suffer from anxiety or mental health issues. However, some neuro-diverse patients may find PIFU less stressful than a fixed appointment.

"People with learning difficulties may find this inaccessible – there is a lot to take in (letter and PIFU process) could be very difficult for people fearful or daunted by the medical profession."

"It's a good initiative if you have ability, capacity and self-confidence to self-manage your condition."

"What about people with conditions such as mental health who may find it difficult to comprehend the process or when they need to make contact for themselves. It might cause further stress."

"How are people in care homes going to be considered under these proposals?"

"People with hearing issues are not always accommodated. Also, translators should be provided but there's no help whatsoever for this currently."

Participants had differing views about whether PIFU would be suitable for patients with neurodiversity. Some felt PIFU could take away a lot of stress of being forced into an appointment and *"reduce difficulties of parents and carers."*

Others felt that *"if all the information comes in different ways (paper, electronic and by text) this is difficult to cope with for some people with neurodiversity challenges or anxiety".*

11. Workshop 3: Reducing Did not attends (DNAs)

Summary note on Reducing 'Did not attends' (DNAs). DNAs are the name given to patients who do not turn up to appointments and participants discussed why this might happen and how to prevent this happening.

Participant information

Continuing the deliberative engagement methodology, participants were given a variety of information about DNAs. All participants were sent some general information on DNAs to read before the workshop. This included some of the reasons the NHS were aware of that lead to DNA. Some of these were within the patient's control (e.g., the patient forgets their appointment) and some of these were due to the system. For example, a patient tried to cancel an appointment but had difficulties in doing so because they had trouble getting through to the telephone number given etc. The information also included some ways that DNAs can be reduced.

During the workshop, before group discussions, all participants were given a presentation by NHS Sussex that showed a recent patient survey which further explained reasons why patients DNA and which areas the NHS could improve to help reduce this number.

Participants were split into the same four groups as before. Two of these groups were given two hospital letters (different letters were given to each group). Each letter advised an anonymous patient that they had been offered an appointment and provided some explanation of the importance of attending the appointment and what it would mean for the hospital if they did not attend. Each letter was worded slightly differently.

Both groups were asked to read through their respective sample letters and consider the following questions in their discussion group:

- Is the information clear, complete, and concise?
- Do you feel this letter could be improved to aid in reducing DNAs?
- Can you see this causing any barriers for particular groups of people?

The other two groups were asked to discuss DNAs based on the presentation by NHS Sussex. These two groups were asked to think about the following in their discussion groups:

- How can we support patients from areas of deprivation and minority ethnic groups attend their outpatient appointments?

To read the full workshop information shared with participants including DNA information, DNA sample letters and the NHS Sussex presentation, please visit participant information.

Findings from the discussion groups

Patient letters
Themes were similar across the two groups that received sample letters. Participants felt that clear, concise information was needed as some of the information in the letters was wordy. Participants agreed the important information should be highlighted at the top of the letter.

Participants also suggested additional practical information (e.g., public transport to, and parking facilities at the hospital) should be included but either on a different page or in an additional leaflet to avoid confusion with the key information. Participants felt co-produced letters with patients could help resolve some of these issues.

Encourage or punish? Supporting patients to avoid DNA
Participants across all four groups debated whether the patient was at fault or there were good reasons for becoming a DNA. Some participants felt that patients who DNA should go to the bottom of the waiting list. Other participants spoke about financial and deprivation reasons that caused patients to DNA. Patients with other responsibilities (children, carers etc.) were also identified as more likely to DNA. Participants felt the current infrastructure did not help discourage DNAs. There were examples shared of patients trying to cancel appointments and not being able to and appointment reminders not being received.

In detail:

What could be improved in the information provided to help reduce DNAs?

Clear, concise information

It was acknowledged that the information included in the letters was comprehensive. However, most participants agreed that the information could be arranged more clearly, to highlight the key appointment information (time, place, medical specialty etc.), on the front page, or in a box with bolded font. Other information such as transport links, maps etc. could be separated out either in a separate leaflet accompanying the letter or on the back of the letter. Some participants made the point that the leaflet with additional information might only be needed by those going to the hospital for the first time. Participants agreed that information should be up to date and accessible language should be used (no acronyms).

"Overall, it's a good letter, information you need is at the top, well-structured."

"This is a typical NHS worded document; the language, the tone & (lack of) simplicity; so wordy, language isn't right. They are not thinking about the recipient."

"First page should only contain the key points succinctly and in bold or a box."

"Perhaps colour coding could be used to highlight the important parts."

"Some of the info was potentially out of date e.g. Covid-related."

"Regular attenders might not need the additional info, just the key details."

Visual aids included in the information

Participants felt that the inclusion of visual aids would help illustrate the information provided in the letters.

"I am a visual learner – so could we have a map?"

"A map to back up the letter could help people to understand and navigate where they need to go."

"If this was my first appointment, I would have had no idea where to go."

Additional information

Participants suggested that all patient letters should include practical information about parking, public transport and how to apply for non-emergency patient transport (NEPTS, NHS England)[12] and how to receive financial support where applicable.

"Could we also get more information about parking in the letters, where is it? What is the cost? And details on disabled parking."

"Also include things like bus routes and train stations nearby."

"Is there a taxi drop-off spot?"

Participants suggested department descriptions should be included and asked for one main number to call for all enquiries. Participants also suggested letters could incorporate the option for patients to advise which days/times they are able to attend an appointment and what type of appointment was preferred.

"Also need more information on what departments are/mean and where they are located in hospitals.

"Have one main contact number for rearranging appointments in the letter, rather than several which causes confusion."

---

[12] NEPTS provide funded transport where a medical condition means that a patient would struggle to safely attend their treatment independently.

"Include options in the letter, of face to face/telephone/video appointments and putting in a graphic to support understanding."

Additional formats for information

Participants discussed the text alert system as being helpful to remind patients about an appointment and suggested frequent reminders, a few days in advance as well as on the day to ensure people don't forget.

"The alert system seems to be reliant on text. "Can there be an alternative format to text-based alert systems? There can be privacy issues with texts and some people don't use texts."

"I recently had a lovely reminder text – but it came a week before – luckily it was an important appointment to me, or I still might have missed it – it should be 24 or 48 hours before – like the dentist."

For some patients it was suggested that text reminders were unsuitable, and alternatives were suggested.

"If the letter was emailed, could it include putting the appointment onto the Outlook calendar?"

"I get a phone call as I don't text. For deprived areas I think a call would be better as texting is technology."

Participants discussed various ways of communicating with patients about appointments and about DNAs.

"The additional information could be located onto a webpage and referenced in the letter."

"This is a very complex issue – over time the NHS needs to customise communications / processes according to KNOWN needs and barriers."

Co-producing patient information

Participants discussed that being presented with a letter for comment was one way to gauge patient opinion in the process, but a better suggestion for next steps, might be to co-design patient information with patients.

"Perhaps co-design a letter rather than be presented with a letter for review; wouldn't this be a better way to do it?"

"The focus on the impact on the NHS of DNAs could put your back up straight away. The letter should be about you, the patient and not about the NHS."

Punish or encourage? Supporting patients to avoid DNA

Punish

There was disagreement amongst participants about whether becoming a DNA was the fault of the patient or the Outpatient system. Some participants wanted to see patients "punished" by cancelling future appointments and/or putting them on the bottom of the waiting list. While other participants argued that there were good reasons for patients becoming a DNA.

"I can't get my head around people not turning up for appointments - every appointment with the NHS is precious especially at the moment."

"I would ban them from future appointments if they are DNA – people need to take responsibility – I know that this is controversial."

"If someone misses an appointment, they should be sent a text / email reminding them and giving the cost of the missed appointment to the NHS."

"The confirmation process should not be seen as punishment as there may be good reasons why they could not attend."

Encourage

There was a recognition that people change their contact details and don't necessarily tell their doctor, so their patient record is not updated. Participants also shared experiences of missing an appointment due to their mobile signal being weak at home. Participants felt patients could be encouraged to re-confirm details including their preferred contact number. This could be reinforced by displaying the latest patient contact information held by services, on all communications with patients.

"Could we include something more regularly in comms/letters to remind people to notify services with changes of details."

"There doesn't seem to be anyway to check if you are on this list, and what number they have for you."

"Telephone appointments need to say on the letter what number they are going to call you on."

"GP to keep patient information up to date, and that's where it all falls down."

"Changing phones and addresses may be an issue. Records must be kept up to date, could well be in short-term accommodation and you can't get to them."

Barriers - Financial / Remote areas

Participants felt that a key barrier to attending all appointments was financial constraints. This could be helped by better provision of more localised services as well as regular reliable public transport to attend services outside the local area. Participants also felt that appointments should be available out-of-hours. Some or all of these were often not available in more remote parts of Brighton and Hove.

"Costs of travel is an issue, plus the cost of texting if you're on Pay as You Go, zero-hours contract, or if they are not living in a place permanently."

"My son is 22 and fell off a scaffold. He is paid by the day, so he was reticent about having a follow-up once he felt he was ok. Out of hours or weekends would help."

"One side of Brighton to another is 3 buses and £15 from one hospital to another, and that's £30 both ways."

"There needs to be more local hubs to help people not needing to spend money to attend appointments."

"I live in the country – there is a limited bus service – especially before 9am – its 20 miles to the hospital – this could make it very difficult to get to hospital on time. Causes stress, it is not just inner city – there are very deprived areas in the countryside."

"The hospital appointment letter should guarantee free travel to get there."

Barriers - Other responsibilities

Participants suggested that additional responsibilities such as caring for others (children or adults), may cause a barrier to attending appointments in person, and/or be a reason for last-minute DNAs.

"Age group issues relate to work and childcare and people unable to reach in person appointments. Is there a possibility of placing more of an emphasis on video appointments for these groups?"

"There needs to be more flexibility /options for people who are working."

"Barriers could be childcare issues."

"There was an evening clinic where I went to (in London). Having the option of evening appointments, may help workers and those on zero hours."

Other barriers and suggested support

Participants suggested other barriers to attending appointments, could be digital exclusion, age, physical mobility, or language. Participants mentioned that support could be provided by making services accessible through translators, choice between face-to-face and remote appointments, and providing physical support for patients arriving at hospital.

"Not everyone has a smartphone or can use it."

"Young people who may not get up early, gender or specialist and religious reasons too."

"Could there be a translation service, so English for the carer and other languages for the patient?"

"Hospital volunteers used to direct people."

Robust infrastructure in place

Participants agreed that any new initiative would need to be supported by the infrastructure. Some participants expressed concern that the current NHS system would not be able to do so and may even benefit from DNAs. Other participants suggested system improvements to discourage DNAs such as sending timely reminders, ensuring publicised telephone numbers are regularly staffed, and not cancelling appointments at the last minute. Alternatively, participants suggested that cancellations could be offered to other patients. In addition, participants suggested that if patients are not valued, this may put them off turning up to an appointment.

Can the NHS support a new initiative?
"I don't understand how the NHS will implement any of this though with lack of funding."

"In my experience appointments generally run very late, so some DNAs might actually help the clinic to run on time!"

"Could the outpatients department cope without the DNAs? I've always waited an hour at least, so people may not feel valued and don't care if they don't turn up."

Suggestions for system improvements
"I had an appointment yesterday – received no reminder – when I phoned they couldn't find it on the system – I booked transport and went to the hospital – they couldn't find the appointment or where I should go – luckily in the end they found it and saw me – a bit late."

"A friend had a recent bad experience – she was given an appointment at a Brighton cancer clinic – she caught the bus to get there – and during her time on the bus they rang to cancel the appointment."

"Experience of ringing several numbers given in a letter and neither of them being answered."

"My wife's and my appointment times were 2 hours apart. Receptionist said we can see you now rather than wait 2 hours, maybe it was a cancellation so there are benefits!"

"The problem starts from the referral to the appointment; if people feel that they are not acknowledged, then perhaps they treat the letter with contempt too and don't bother turning up and don't feel bad about it."

12. Workshop 4: Suggestions for a better system

Participant information

The fourth and final workshop provided an opportunity for participants to reflect on their knowledge of the outpatient system. In line with the deliberative engagement process, participants had received information within and between workshops, including presentations, scenarios, and other participant information. They had also been encouraged to consider other viewpoints having taken part in group discussions.

At the beginning of this fourth workshop, NHS Sussex presented a short re-cap of the aims of the outpatient transformation and the initiatives that had been proposed. Participants were then separated into the same four breakout groups as previous workshops and were asked to focus their discussion on the following question:

- If you were going to transform the outpatient system, what would you do?

Participants were also asked to write into the chat function, any further questions they had for NHS Sussex. To see the presentation by NHS Sussex, please visit participant information. To view the further questions asked by participants in the chat and responses from NHS Sussex, please see Appendix B.

Findings from the discussion groups

Discussions across all four groups drew out similar themes and these are collated in the findings below.

1. Participants agreed that certain things were important for the success of all initiatives proposed. At the heart of this was involving the patient throughout the process.
2. Participants agreed that patients should be involved in any decisions, from making a diagnosis and planning treatment to a patient's preferred form of appointment.
3. This needed to be coupled with ongoing communication to keep the patient updated with where they are in the system.

4. As the patient journey started with the GP, participants stressed how important it was for the GP to be up to date with information, and to have time to listen and respond empathetically to the patient.
5. Where patients had additional needs or needed extra support, this should be noted on patient records and play a role in the way they were treated throughout their healthcare journey.
6. Participants also stressed the importance of a robust infrastructure to support all the initiatives proposed.

In detail:

Involving the patient throughout the process
There was consensus from participants, about involving the patient more in the outpatient system. This could be offering patients options including self-referral and providing explanations in easy to understand language. For example explaining why a referral was needed, and explaining test results.

"Any reviews also need to include everyone, patients and staff."

"When GP says they are referring it would be good to get options at this point on where you can have treatment."

"At the point of referral, can a number be given for the patient to book the appointment, so they are controlling it, rather than the appointment being made for them (even if it's a long wait)?"

"'Outpatients' is an intimidating term; a lot of people don't know what it means."

Participants asked why patient contact details were not regularly and systematically updated. A patient's preferred communication format (email, letter, phone call) and preferred appointment format (face to face or virtual) should be noted as well as whether a patient would be able to accept a last-minute cancellation appointment. Patient records should

also identify where a patient has specific needs that does or may make accessing services difficult.

"There could be something to be said for notes going with patients themselves."

"I was not on the system (NHS App) as a referral and my GP advised I was 'in the process of being referred'. What about a self-referral option?"

Communication

Participants agreed that consistent, regular patient communication was key to the success of all the proposed transformation initiatives. From GP appointments, explaining the initial referral, to keeping patients in touch with where they were in the queue would help ease stress and worry. If patients were given realistic wait times for the consultant to respond to the GP (A&G) or for the referral to become an appointment, this would avoid unnecessary follow-ups.

"Trust comes with good communication."

"Keeping in contact, even if it's just to say we haven't forgotten you."

"Informing the patient of timescales, could avoid unnecessary follow up calls."

"Consistency of information is key. Patients will be willing to wait if they have some information."

"Appointments are still sent via snail mail. Why not email if this works for results?"

Time for talking

Continuing the theme of communication, participants felt that doctors should have more time to listen and for patients to explain the context of what's going on. Participants shared experiences of calling to make an appointment and speaking to practice staff covering a position temporarily, and being made to feel as if they were taking up the person's time.

"Conversations are as important as treatment."

"Interactions need to be meaningful not just a tick box exercise otherwise we are just getting an unsupported pathway, that doesn't help patients and only adds to the staff pressure."

"Daughter waited six weeks for an appointment to be told at the appointment that the GP did not have the time to deal with more than one problem."

GP responsibility

Participants discussed how the patient journey starts with the GP and if the doctor is not well informed with up-to-date information, this may not be passed to the patient. Participants discussed how GPs are stretched and sometimes they make the wrong call with referring for unnecessary treatment and the A&G initiative may help avoid this happening.

"What will give GPs confidence NOT to refer you?"

"There are not enough GPs so they are overworked; other clinicians and non-clinicians should be doing the admin work for the patient."

"It is all down to primary care. If your doctor doesn't have the info they need, none of this will happen."

Community services

Participants discussed positive experiences of local services and how access to more community services could avoid the need for patients to travel further.

"I have seen a consultant at a local surgery so saved lots of time – six weeks as opposed to five months. Taking the clinic to the people rather than people to the clinic."

"Keep pharmacists in the loop and make sure they have leaflets about the pathway too and the new initiatives."

"Some of us are lucky to have a really good local GP surgery with a mix of staff and services offered…creates the powerful relationship of trust."

Robust infrastructure

Participants agreed that any new initiative needs to be supported by a robust infrastructure. This starts with good communication throughout the health system, with GPs and consultants working in a joined-up process and ensuring all health systems offer a consistent standard of service. There was also concern about the implicated costs for this system to work, for example providing enough time for GPs to listen to the whole patient story in a holistic way.

"Think about passive messaging e.g., banners in GP surgeries to clarify the process; GPs can explain the process like 'advice and guidance' to the patient but not all patients will be IT literate so a nice handout for patients to take home and mull over. And get all the Apps together like the NHS App, Patient's Know Best; and various emails about 'your health record has been updated'."

"Getting the results from tests following the outpatient appointment. Knowing who you get the results from, the GP or consultant. It takes ages for the consultant to write to the GP."

"It's a postcode lottery about what you get. At King's there's a phlebotomist available all day, until 7 pm at night but this is not available everywhere. Not in Worthing where I had to wait six days for an urgent test."

"Are we taking money from other services to fund this?"

Centralised services

Participants called for a centralised system with better communication between different specialities and different hospitals. This was particularly relevant to introducing Patient Choice, asking people to go out of their local area to attend an appointment where the hospital may not understand their medical history. One participant had recently heard on the radio about a GP tracking system where GPs are able to see a patient's whole experience throughout the system, and this could enable them in having a better understanding of their patient.

"What about a one-stop shop for test and appointments rather than a test and then having to come back for an appointment."

"All clinics in South Africa are self-contained – where you have all sorts like ultrasounds, consultants, hospital beds. Just doesn't make sense that they have such big hospitals."

"The system needs to be better organised, so there aren't duplications or clashes of appointments for those patients with more than one condition."

"Are consultants now able to refer between consultants rather than having to send the patient back to their GP? Also, can there be referrals between other health care professionals?"

"The delays between seeing a consultant and letting the GP knowing what happened are too long."

Technology

Participants discussed the use of technology to support the initiatives, such as Telecare technology. Some participants shared their experiences of using technology, both positive and where it generated challenges.

"I was gobsmacked about the system. Did an e-consult, told to go, and meet my GP about 45 minutes later, spent ages with him, referred and had an x-ray the following morning, had a blood test with results within 24 hours. Electronically it was so seamless but manually it would take so much longer."

"It's all to do with communication about going for tests and getting results and technology really helps with that like telephone and video, it saves time."

"Problem I have is when people text you and you may lose that text and then you can't communicate with them." Another participant suggested "take a screen shot so you've got a record of it in your photos."

Other participants mentioned ways in which technology could be used, such as websites that hold patient information for example, 'Patients Know Best' and 'Patient Access', electronic screens in GP surgeries and the use of medical Apps.

"Should encourage use of websites like Patients Know Best."

"Use screens in GP surgeries to communicate messages especially re DNA's."

"There are so many devices available these days, e.g. ones that link to an app (e.g. blood pressure monitor) – more of these will keep people out of outpatients; particularly if the data captured is made available to clinicians."

Triage system to identify needs
Participants felt within the system there needed to be a way of identifying patients with additional needs. Participants discussed including this information on the patient's notes (mentioned earlier), and the idea of a triage system whereby someone with additional support needs would be identified and supported early on.

"Could we have a sort of outpatient triage system, that helps those with barriers become identified and then helped in terms of accessing and navigating the system?"

"Some people need more support than others."

"There should be more kindness and respect for different people and their needs. Sometimes you can be "shut down" for not being an expert or knowing what the terminology means."

"Knowing what it is to make things work for that patient can work towards avoiding missed appointments."

Patient responsibility

Participants also acknowledged that sometimes the patient is at fault and there were some strong views around patient responsibility for becoming a DNA. Some participants felt that the NHS is wasting money on patients who regularly DNA and suggested penalties. However, other participants defended the reasons behind DNAs and suggested the NHS cannot be compared to a private organisation like a dental practice, and could not support a penalty scheme due to the administration involved.

"I don't necessarily agree with sanctions, but we need to do something to reduce regular DNA's."

"What about a deposit style system that is used by some dentists?"

"If you want to be treated you have to make an effort."

"DNA's have an effect on other patients' care."

"Patients need to be active in their own treatment. Confirmation of attendance should be a necessity, otherwise the slot may go to someone else."

13. Workshop 4: Communicating the outpatient transformation to the wider public

Participant information

The second half of the final workshop focused on communicating the initiatives proposed for transforming the Outpatient system, to the wider public.

As before, participants were separated into the same four breakout groups and were asked to consider the four transformation initiatives i.e., A&G, Utilising System Capacity (Patient Choice), PIFU and DNA. In their discussion groups, participants were asked to focus on the following question:

- How would you go about telling the wider public about the four initiatives we have discussed? You may wish to think about this in the context of patients sitting in a GP waiting room or in the hospital or elsewhere.

Findings from the discussion groups

Themes were similar across all four discussion groups and have been collated below.

Participants discussed the need for information to be available in a range of formats, digital and traditional, ensuring it was clear and accessible. Communication should be widespread, national as well as local and available in health and non-health related settings to ensure it was seen by as many people as possible.

Participants felt there was real benefit to be gained from working with local organisations who were already set up to engage with patient groups. The NHS should also participate in face-to-face engagement. In addition, health providers had a responsibility to ensure their staff were well informed of any new initiatives.

In detail:

Communication format (WHAT)

Participants discussed the need for both digital and physical communication. For example, physical leaflets and posters alongside websites, social media, and text messaging. It is important that all communication was accessible, clear, concise, and available in different languages. Individual preferences should be considered, for example some participants felt "bombarded" with emails while others preferred this form of communication.

"The material must be in different languages."

"Not too many words."

"Adverts, posters etc could have a QR code to take people to a website."

"Targeted texts during the pandemic were effective and told you what was happening and what to do about it."

"Accessibility standards are well known. All letters should be in large font (14 point or above)."

"The NHS should take people's individual needs into account."

Spreading publicity (WHERE)

Participants discussed the need for publicity that was broad enough to reach people at home (e.g. the elderly, people cared for etc.) as well as those who are digitally excluded. Participants discussed TV and Radio broadcasting, both nationally and locally in addition to the channels available in the GP surgery.

"BBC South-East, ITV etc. to have discussions about these initiatives on their news programmes."

"Local radio for retired people, they are always thirsty for topics."

Participants also suggested displaying printed communication such as posters in community settings, as well as health centres. Participants suggested using existing communication methods such as Patient Access and including information in appointment letters.

"Local, often free newspapers with a good visual presentation."

Leaflets in doctor's surgeries, chemists and anywhere where healthcare is provided."

"Use ads (e.g., before the News) or posters in bus shelters."

"Leaflets/posters in libraries…"

"Information in food banks which will reach certain groups."

"To target younger people, we need to use the education system and signpost in these settings."

Other participants talked about online options, such as social media and websites.

"For those digitally capable, create a website of information, make it interactive."

"Social media for young people – short & punchy facts, including a way to ask questions without needing to involve your GP."

"However, be careful of the potentially harmful information-gathering algorithms that can be abused by social media."

Strategies (HOW)

Participants suggested using communication channels that already exist, such as local organisations, including Local Healthwatch, etc. Participants acknowledged that there were so many audiences and people, that any communication would need to be both diverse and multi-faceted and over a length of time, to ensure real impact. This should also include a two-way approach, ensuring opportunities for patients to feed back to practitioners as well as providing patients with information.

"NHS Representatives should be going into community groups."

"Introduce digital ambassadors to make sure messages aren't siloed."

"Many community groups are already involved with hard-to-reach people."

"Ensure GPs and other health professionals (social workers, care providers, carers) know about these initiatives and tell their patients."

"Perhaps a face-to-face approach, like an outreach/roadshow type of thing. Healthwatch could run the workshops perhaps?"

Some participants warned against communicating too widely or too early. *"Don't get too ambitious about everyone needing to know. We should aim to reach people at the point when they need to use it."*

"The danger about advertising something that your GP isn't currently offering."

14. Conclusion

Participants brought their own experiences about outpatient services to the workshops. These included difficulties with booking systems and waiting times and a shared frustration with the lack of communication received as a patient once in the system. Participants spoke about the lack of time for medical staff to understand and treat the patient as an individual.

Through the deliberative engagement process, participants became increasingly knowledgeable about the outpatient system in Sussex. This was demonstrated both through the use of polls at the beginning and end of workshops, as well as the positive comments made by NHS Sussex staff. This methodology enabled participants to look at the proposed transformation more objectively, and from the point of view of other patients as well as themselves.

Participants expressed similar views and concerns across all four discussion groups when looking at the proposed transformation:

- Participants thought Advice & Guidance made good sense in theory but were concerned that some conditions and some individuals were not suitable for this system. Patients should be included in the communication between GP and consultant to ensure its success.

- Participants felt that Utilising System Capacity (Patient Choice) could help local demand. However, this may exclude patients if the offer involved travelling further than their local hospital. Participants advised that continuity of care between local and alternative services was crucial to its success.

- Participants felt Patient Initiated Follow-up was a good example of giving patients some control over their own healthcare journey. However, some patients would need additional support and for other patients, PIFU may not be suitable.

- Participants disagreed with one another about patient responsibility around reducing Did Not Attends. Some participants felt that DNAs should go to the bottom of the waiting list. Other participants

suggested that financial challenges and/or geographical remoteness were understandable reasons for patients to DNA.

- As the patient journey started with the GP, participants stressed how important it was for the GP to be up to date with information, to give time to listen and respond empathetically to the patient. Where patients had additional needs or needed extra support, this should be noted on patient records and play a role in the way they were treated throughout their healthcare journey.

- Participants agreed that a robust infrastructure was needed for the transformation to succeed. Some examples of this might include, but are not limited to:
  - Ensuring enough capacity to provide a dedicated PIFU phone line.
  - Ring-fenced consultant time to provide advice & guidance to GPs.
  - Continuity between local services and any alternative provider offered through patient choice.

- Participants were shown several samples of patient information. Across all samples, similar observations were raised, namely:
  - Information was sometimes lengthy and unclear, and the important information was hidden amongst additional practical information.
  - Some practical information was not included, such as public transport information.
  - Information was text-heavy and some of the information needed to be explained.

- These observations on patient information (above) were also felt to be relevant when thinking about communicating the transformation to the wider public. In addition, participants felt publicity should be widespread and local organisations could be helpful in promoting this. Participants felt that information should be in various formats to ensure accessibility.

To ensure the transformation was effective, participants felt patients should be kept at the heart of all proposed initiatives and that patients should feel able to speak up about their care, asking for clarification and

becoming active users rather than passive recipients of healthcare. Where patients have additional needs, whatever these might be, all medical staff should be aware and treat the patient accordingly. Up-to-date patient records would enable medical staff to be aware of these.

Patients and their carers should be involved in decisions about their health, and part of the conversation between medical staff concerning their treatment. Patients should be kept informed of where they are in the system and how long they must wait for treatment, referrals etc. At best, co-production would enable patients to directly influence patient information.

15. Next Steps and Impact to date

On 21st September, Healthwatch Brighton and Hove presented the findings and recommendations from these workshops to NHS Sussex.

In response, the Head of Outpatient Transformation and the Director of Elective Care provided a verbal update on the impact to date, resulting from the outcomes of the outpatient workshops.

Below is a summary of this verbal update on impact:

Patient portal

NHS Sussex are one of three systems in the UK who are piloting an expanded version of the NHS App. This will provide patients with notification of an outpatient appointment, reminders prior to the appointment. It will also enable patients to respond and confirm if they are able to attend the appointment. If they are unable to do so, patients can request an alternative date. Patients who need ongoing treatment will be given an early health screening to "wait well". For example, this could be support to lose weight or stop smoking.

This App should help address some of the issues noted in the workshops around DNAs, where patients sometimes didn't know that an appointment had been booked for them, or were unable to change it if inconvenient, and were unable to find out where they were on the waiting list.

This App is being rolled out to East Sussex hospitals on 30th September, to University Hospitals Sussex NHS foundation trust on 6th October and to Queen Victoria hospital, West Sussex on 31st October.

GP involvement

NHS Sussex has been working with GPs from the outset of these initiatives and they have representation on a newly formed clinical reference group, to enable co-production of initiatives. This reflects the comments made during the workshops about the importance of involving GPs as the first point of contact for healthcare.

Advice and Guidance

NHS Sussex have focused on improving turnaround time of advice and guidance from consultant to GP. Developing a feedback method for GPs to report any concerns they have on the advice they receive, this goes directly to the specialty to help improve the service. This reflects workshop comments around ensuing advice provided to the GP is accessible.

The next stage will be to look at the process in general, ensuring the infrastructure is there, to enable specialists to respond in a timely manner and providing support to GPs to ensure the process works. This reflects workshop comments around infrastructure and training/support for GPs.

Patient choice (Utilising System Capacity)

An NHS Sussex team has been developed to focus on a system-wide approach for patient choice. The focus is on a digital approach to ensure notes are available across different providers. Workshop findings have been shared with this team and are being applied in the system development.

The patient portal will also provide an opportunity for patients to indicate if a) they are willing to travel, and b) if they are able to attend an appointment offered at short notice, due to a cancellation. This information will be stored on the App.

Patient Initiated Follow-up

National communication in the form of a patient-focused video has been shared with all hospitals in Sussex. Workshop findings have been shared with PIFU leads in each Trust, to ensure these are embedded in their plans. This includes participant feedback on patient information that was reviewed in the workshops.

Did Not Attends

The Patient Portal is key to helping reduce DNAs. As a result of workshop feedback, NHS Sussex are focusing on helping support those groups who find it difficult to attend appointments. NHS Sussex are linking in with voluntary sector agencies to help support these patients.

Early conversations are being had to work out how to record information that helps identify these patients.

Workshop feedback responding to DNA sample letters is being taken into consideration, particularly the use of language and tone. Participants suggested using language that encourages rather than criticises patients. NHS Sussex are looking to incorporate maps and other visual aids as suggested by workshop participants. NHS Sussex are also including links to (hospital) websites with additional information to simplify letters, again in response to workshop feedback. The patient portal provision of digital information will also help reduce the need for lengthy letters.

Communications and national impact

NHS Sussex have begun work with the Amex to place an advert in the stadium, about the initiatives that are being introduced.

NHS Sussex are also represented on the NHS England "national missed appointments" meeting. Sharing feedback from the outpatient project is having an impact on the national system.

16. Appendices

Appendix A: Screening questions

HWBH carried out a screening process for all applicants who showed an interest in being involved with the workshops. HWBH sent out a set of screening questions by email, which required qualitative as well as quantitative responses, to ensure responses were genuine and not automatic. The template email and questions are shown below:

Dear [name],

Thank you for your interest in becoming a participant for the Outpatient Transformation Workshops. We have heard from a lot of people and there is a limit on the number of participants we can take on board.

Therefore, please find below a set of questions that we politely ask you to respond to. This will give us an idea of you and your experience of Outpatients and enable us to choose a group of participants that will represent a variety of interests and experiences.

Apologies if you have answered some of these questions in your original email.

Please can you send me your responses as soon as possible, and preferably by **[date].**

Many thanks

Michelle

Q1.   Taking part in the project requires attendance at all four workshops. These have been booked for **11am - 1pm** on the following dates: **20th April, 27th April, 4th May and 11th May 2023**. *Please also allow for an additional 15 minutes before the workshop as we will invite participants to log on early to ensure that everyone has connected successfully via internet*.
Please confirm that you can attend all four dates and these times.

Q2.   In the last two years, have you attended or are you waiting for an Outpatient appointment?
- I have attended an Outpatient appointment in the last two years
- I am on the waiting list for an Outpatient appointment
- I have not attended an Outpatient appointment in the last two years and am not on the waiting list.

Q3.   Which hospital did you attend for this appointment/are you waiting to hear from for your appointment?
Please provide the name of the hospital:

Q4. What was the Outpatient appointment for? It is not necessary to give specific details, but we are interested in the speciality e.g. physiotherapy, Urology, Cardiology, etc.
Please specify the type of Outpatient appointment

Q5. Was your experience of booking the appointment positive, negative or a mixture? **Please provide a *sentence* describing your experience.**

Q6. **Was the appointment for yourself or for someone you care for?**

Q7. How would you describe your ethnic background? (for example, Asian OR Asian British OR White British etc.) **Please describe your ethnicity briefly below (please state if you would prefer not to provide this information):**

Q8. **What age are you?** If you do not wish to give a specific age, please provide an approximate one e.g. 30's, 40's, 50's etc. Please state if you would prefer not to provide this information.

Q9. **What gender are you?** (female/male/non-binary etc)

Q10. **How would you describe your sexual orientation** (Lesbian, gay, straight, bi etc.)?

Q11. **Are your day-to-day activities limited because of a health problem** or disability which has lasted, or is expected to last, at least 12 months?

Q12. If this is a yes, can you **describe the type of impairment** e.g. physical or sensory impairment, mental health condition etc.

Q13. **Do you care for another person**, friend, family in an unpaid capacity?

Q14. **Please confirm which part of Sussex you live in?**
- Brighton and Hove
- East Sussex
- West Sussex
- I live outside Sussex

Q15. Please can you provide us with a mobile telephone number or UK-based landline number, and confirm which days/times it is best to call you for an informal chat to explain more about how you can take part. Please specify the day(s) you would prefer to receive a phone call and whether you would prefer to be contacted morning or afternoon:
Your mobile/UK telephone number:
The days you would prefer to be contacted, and your preference for morning or afternoon:

Appendix B: Additional participant questions

During Workshop 4, participants were asked to put into the chat box, any further questions they had for NHS Sussex.

Participants asked several questions about PIFU. NHS Sussex explained that PIFU was a national programme with an agreed target to achieve. Some services are already using PIFU and need to increase use, some services have not yet implemented PIFU. There are differences across hospitals which means the approach may need to vary. Firstly, the clinical criteria has to be agreed by the consultants and then the teams need the resources in place to respond to patients when they request an appointment. NHS Sussex were currently reviewing which services are suitable for PIFU and deciding where to focus. The team are also considering patient information to support this initiative.

Participants asked whether consultants would have the time to respond promptly to A&G queries on top of their usual work. NHS Sussex explained that their working schedules had protected time to respond to A&G concerns from primary care. In some services this needs to be increased.

Participants asked about confirmation texts and NHS Sussex confirmed an important part of the transformation was enabling patients to confirm attendance or cancel an appointment, with the latter linking in with the appointment booking system and freeing up the cancelled appointment for another patient. There are also plans to have a patient portal which will have text and telephone reminders and allow patients to cancel and rebook their own appointment.

Participants asked about keeping patients in the loop about new initiatives and NHS Sussex explained that part of the workshop today was talking about how best to communicate the initiatives to the wider public and ensure they are aware of these new initiatives.