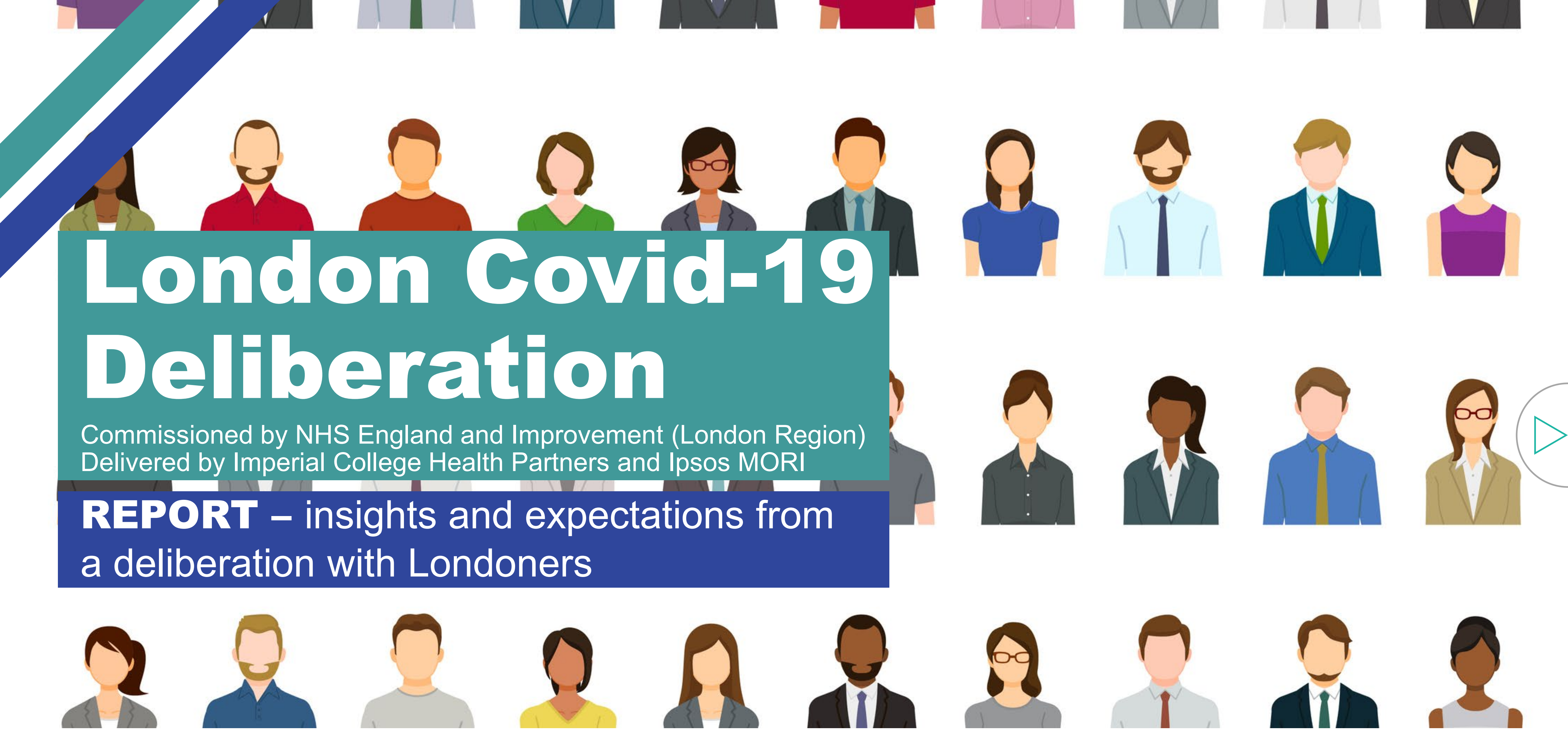


London Covid-19 Deliberation

Commissioned by NHS England and Improvement (London Region)
Delivered by Imperial College Health Partners and Ipsos MORI

REPORT – insights and expectations from a deliberation with Londoners

July - August 2020

Foreword

Dear Colleagues,

The coronavirus COVID-19 pandemic is the defining global health crisis of our time and the greatest challenge we have faced in the NHS.

In London, thanks to the professionalism, flexibility and courage of our staff, we have made many changes to the way in which we work and provide services to meet these challenges. These changes have enabled the NHS to move quickly into a recovery stage and return, as far as is possible, to business as usual.

But they have also presented opportunities for new policy directions and the long-term development of the NHS and that is why listening to the views and insights of Londoners has been an essential part of the process.

The impact of the Covid-19 public health emergency meant that a quick response to shifting priorities was essential as part of the NHS's ongoing response and recovery to the disease. Measures had to be implemented quickly, which also meant that a new, quick and effective way of engaging with the public had to be found.

Over six virtual workshops, 18 hours in total, 60 Londoners deliberated in depth the challenges and opportunities facing the NHS, supported by clinicians from across the NHS in London. The process, an inclusive approach which also involved people from marginalised communities and those worse hit by the pandemic, was supported by National Voices, Healthwatch and numerous advocacy groups.

The NHS in London has been able to listen to a group of citizens, reflective of the wider London population, to inform decisions that will be made in the next phase of the pandemic. Crucially this work has also involved gaining considered insight into what matters most to Londoners, using emerging policy proposals like those on elective or planned care, virtual appointments and access to urgent and emergency care.

We then deliberated the findings from this 'London dialogue' with Londoners to talk about the choices we will face and the inevitable trade-offs that we will need to make as we build and adapt for the future. It was immensely beneficial to hear what the public thought and to be able to map-out expectations for the journey we will continue to take together.

We undertook this innovative approach to fully understand how Londoners not only felt about the changes that have been put in place as part of the emergency response to Covid-19, but also what their views and expectations are in relation to potential future changes.

Over the summer, we have done everything we can to ensure that NHS in London is prepared and has capacity to cope with additional demand this winter. We are introducing a number of initiatives, supported and informed by this project, to ensure that every Londoner can access the NHS when they need us as safely as possible.

I am immensely grateful to everyone who has supported us in this pioneering work to ensure Londoners are the heart of our services in the NHS. Furthermore, I will continue to be proud of our NHS workforce who have bravely supported and protected the people across our capital.

Best wishes,

Sir David Sloman

Context for this work

In response to the Covid-19 public health emergency, rapid change was implemented across all levels of the London health and care system. Measures were implemented at pace and therefore engaging with the public on these was extremely challenging. It is important to understand how Londoners feel about the changes that have already been put in place as part of the emergency response.

Further, as the NHS plans its response to the next phase of the pandemic in the Capital there is an opportunity to explore Londoners' expectations in relation to mid to longer-term measures and in particular the dilemmas and trade-offs these may create.

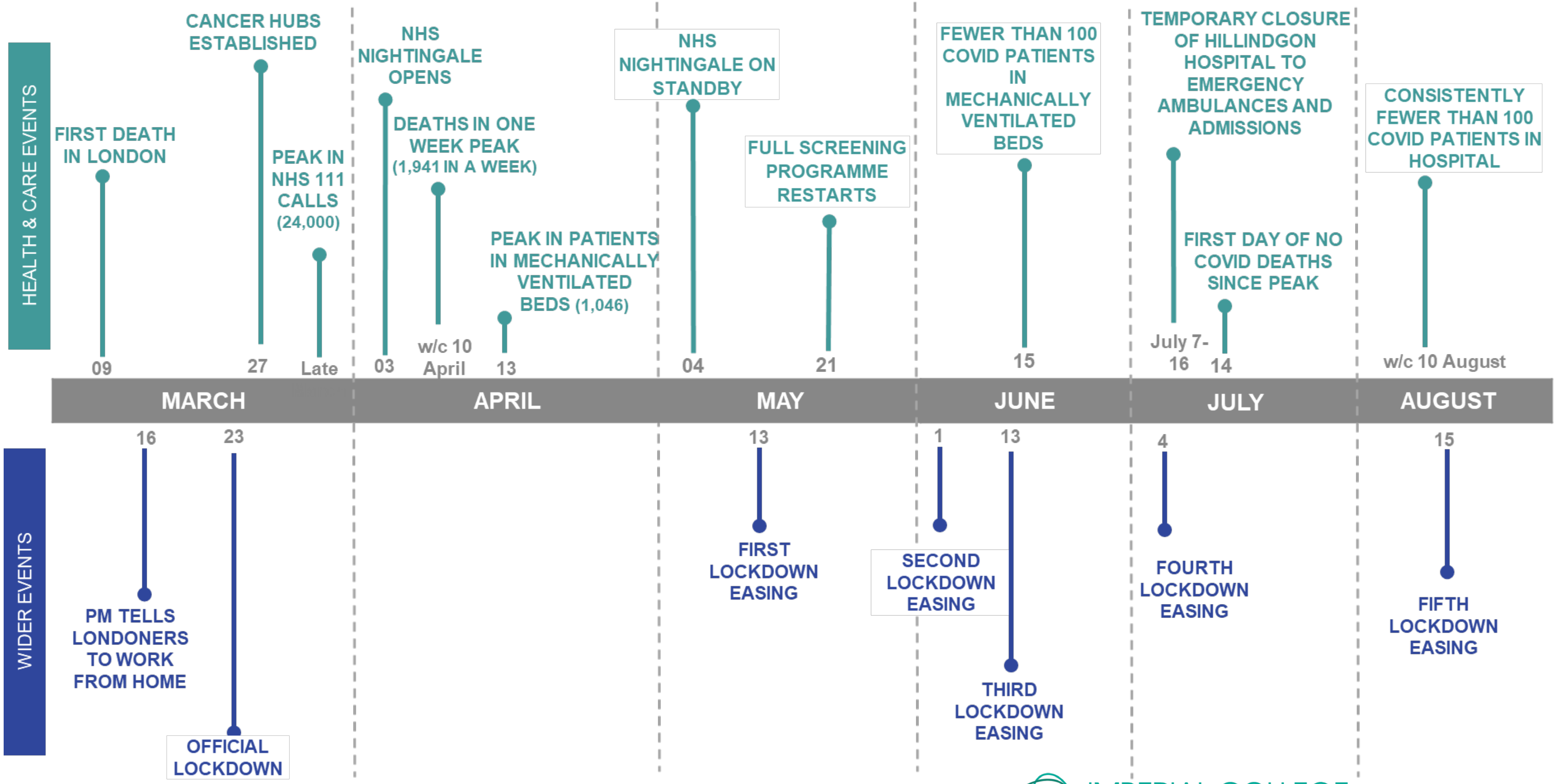
Working with Londoners, through a process of dialogue and deliberation, NHS England and Improvement (London region) commissioned Imperial College Health Partners (ICHP) and Ipsos MORI to deliver a two-stage dialogue and deliberation project. The aim was to explore the dilemmas relating to emerging policy proposals in partnership with Londoners to understand their expectations and inform future decision-making relating to the response to the pandemic, specifically exploring the tensions and trade-offs.

The intended output was an informed and considered set of expectations to guide future planning and further engagement at ICS level as further changes are made in response to the pandemic.

The participants were directed to develop these expectations as guiding statements that are not binding, but rather will assist the NHS when making decisions about services during the pandemic.

It should be noted that this engagement took place during a period where policies in response to the pandemic were forming at a rapid pace. Some proposals and ideas discussed during the process have since evolved or changed. This report sets out participants' views in relation to the proposals and ideas presented to them at the time, rather than current day policies. This process complements local engagement activity and should not be confused with formal public consultation.

COVID-19 timeline for the NHS in London



HEALTH & CARE EVENTS

FIRST DEATH IN LONDON
09

CANCER HUBS ESTABLISHED
27

PEAK IN NHS 111 CALLS (24,000)
Late

NHS NIGHTINGALE OPENS
03

DEATHS IN ONE WEEK PEAK (1,941 IN A WEEK)
w/c 10 April

PEAK IN PATIENTS IN MECHANICALLY VENTILATED BEDS (1,046)
13

NHS NIGHTINGALE ON STANDBY
04

FULL SCREENING PROGRAMME RESTARTS
21

FEWER THAN 100 COVID PATIENTS IN MECHANICALLY VENTILATED BEDS
15

TEMPORARY CLOSURE OF HILLINGDON HOSPITAL TO EMERGENCY AMBULANCES AND ADMISSIONS
July 7-16

FIRST DAY OF NO COVID DEATHS SINCE PEAK
14

CONSISTENTLY FEWER THAN 100 COVID PATIENTS IN HOSPITAL
w/c 10 August

MARCH
APRIL
MAY
JUNE
JULY
AUGUST

WIDER EVENTS

16
PM TELLS LONDONERS TO WORK FROM HOME

23
OFFICIAL LOCKDOWN

13
FIRST LOCKDOWN EASING

1
SECOND LOCKDOWN EASING

13
THIRD LOCKDOWN EASING

4
FOURTH LOCKDOWN EASING

15
FIFTH LOCKDOWN EASING

Contents

Executive summary

A deliberation exploring what matters most to Londoners to inform the next phase of the pandemic response by the NHS in London

Overview:

This report presents the findings from the second stage of a dialogue and deliberation engagement programme conducted by Imperial College Health Partners and Ipsos MORI on behalf of NHS England and Improvement (London region). Following two dialogue workshops conducted in June, the second stage of the research comprised four deliberative workshops with Londoners who explored some of the genuine dilemmas faced by the NHS when developing policy interventions as part of the next phase of the pandemic response.

Its overall aim has been to explore Londoners' expectations of the mid to longer term measures that could be put in place in response to the pandemic and the potential implications of these.

The research has culminated in the development of Londoners' expectations, a set of guiding statements that are not binding, but rather are intended to assist the NHS when making decisions about services during the next phase of the pandemic.

Methodology:

This phase of the project involved four virtual deliberative workshops comprising 59 Londoners recruited across the five London STPs/ICSs.

Each workshop lasted three hours and included a combination of presentations informing participants about specific areas of policy, and group discussions in which smaller groups of around six participants reviewed stimulus materials and deliberated their views, experiences and expectations.

This phase of the project builds on two virtual dialogue workshops conducted in June with the same participants, designed to bring participants up to speed and begin generating insight.

Alongside the dialogue and deliberation programme, additional engagement was carried out with advocacy groups representing under-represented and vulnerable communities, and people with lived experiences to further inform the outputs.

Policy areas discussed:

A number of potential policy areas and ideas were discussed with participants, which at the time of the discussions were proposals or ideas rather than established policy. Since the workshops, policy has further evolved and sometimes moved away from these proposals.

Policy areas that participants deliberated (1)

It is important to note that the measures discussed at the time of the discussions with participants were proposals rather than established policies. Since the deliberative workshops, some of the proposals have changed or further evolved. This report sets out participant views in relation to the proposals and ideas presented to them at the time, rather than current day policies. These are summarised as follows:

Prioritisation of elective care

The NHS cannot treat everyone at once and more people are waiting longer for treatment as a result of many elective services stopping during the height of the pandemic.

There needs to be a way of prioritising patients who are waiting for treatment. We refer to this throughout the report as prioritisation, or prioritisation of elective care.

Deferring treatment

During the pandemic, some patients who have been scheduled to come into a hospital to receive their planned treatment have requested to delay their procedure due to fear of contracting Covid-19.

The NHS needs to manage these situations with patients to ensure that they are not put at more risk because of their condition.

Consolidation of elective care

Whilst the rates of Covid-19 infections decline, the NHS needs to think differently about how it delivers services so as to continue to minimise the risk of infection for patients and staff, and manage the risk of a second or subsequent wave.

To do this, some services will be consolidated to enable patients a space to be treated where the risk of Covid-19 infection is significantly reduced. We will refer to these potential changes as the consolidation of elective care.

Policy areas that participants deliberated (2)

It is important to note that the measures discussed at the time of the discussions with participants were proposals rather than established policies. Since the deliberative workshops, some of the proposals have changed or further evolved. This report sets out participant views in relation to the proposals and ideas presented to them at the time, rather than current day policies. These are summarised as follows:

Self-isolation

Historically, national guidance implemented for infection control during a period of high Covid-19 community transmission required people to self-isolate before being admitted to hospital for a procedure.

They were asked to self-isolate for 14 days, along with other members of their household. Patients were asked to only attend hospital if they had no symptoms and (where feasible) if they have had a Covid-19 test with negative results 72 hours before admission. We will refer to this throughout as self-isolation.

Virtual first

Patients’ first contact with health services will be virtual where possible in order to minimise infections.

This does not mean that patients cannot see someone face-to-face, but it is the first step to accessing the support they need. Virtual refers to phone, video and digital correspondence like apps and email. We will refer to this proposed policy change throughout as virtual first.

Access to urgent and emergency care

In the context of the pandemic, it was proposed that patients should be encouraged to call 111 first rather than going directly to A&E or an Urgent Treatment Centre (UTC), in order to reduce the volume of people in A&E waiting rooms and therefore reduce the risk of contracting Covid-19.

The proposals set out that those seeking urgent or emergency care would be transferred or called back by a clinical advisor; those who required it would be given an A&E/UTC appointment; and those with less severe conditions would be given remote advice or be referred somewhere else that can appropriately meet their needs.

Key themes from the deliberation with Londoners

- There was an enormous sense of pride in the NHS and its staff. Participants understood the difficult challenges faced by the NHS and were keen to do what was needed to support it.
- In the context of the Covid-19 pandemic, participants were generally accepting of the need for change and the reduction of choice some of the measures discussed might result in.
- However, participants raised a number of concerns around the practicalities of how the different measures discussed during the workshops would be implemented.
- Key among these was how changes to services would affect different groups of people, particularly those considered more vulnerable. They wanted the NHS to show some flexibility and adaptability towards patients in vulnerable circumstances to avoid further exacerbating any existing inequalities.
- Participants felt safety and reassurance should be at the core of every communication with the public. Linked to this, they thought the public need to understand the rationale behind each policy change.

Participants were, overall, accepting of the proposed changes given the context of the pandemic

Prioritisation in elective care:

The need to prioritise patient lists was generally accepted given the current circumstances of the pandemic. However, there were concerns about the length of waits (some participants wanted the length of wait to be limited to a certain level). Overwhelmingly, participants' main consideration when prioritising patients was clinical severity, which included judgements of how life-threatening the condition was, its potential for deterioration and other risks facing patients. Following this, the inter-linked factors of the patient's level of pain, quality of life and age was important. Other secondary considerations included the impact on the patient's mental health and their employment and financial status.

Deferring treatment:

Participants emphasised the importance of informed choice when patients make decisions about their treatment. For those requesting to delay treatment due to fear about contracting Covid-19, a cooling-off period was widely supported. Overall, participants believed patients who wanted time to consider their decision should be able to go back on the waiting list at the same point as when they entered the 'cooling-off period' during which they were making a decision. However, they generally agreed the cooling-off period should not be long (2-4 weeks). Finally, there were some concerns expressed over whether everybody had the capacity to make an informed decision.

Consolidation of elective care services:

For most, the consolidation of services into elective care centres and diagnostic hubs was welcomed, with the positives clearly outweighing the negatives – even in the absence of Covid-19. Alongside reducing the backlog in waiting lists, perceived positives included safety from Covid-19, staffing efficiency, and access to high quality care.

While participants were willing to compromise on choice, they recognised the importance of still offering it for people in vulnerable circumstances (for example, those not able to travel easily, those needing regular care, and those who want or need continuity of care above anything else).

Self-isolation:

At the time of the workshop, the 14-day self-isolation national standard prior to a procedure was in place due to high levels of Covid-19 community transmission. Although the requirement for patients to self-isolate before a procedure was perceived as necessary, participants thought that the 14-day standard was unrealistic.

Clear guidance and instructions about what patients should and should not be doing before a procedure was viewed as a sensible alternative for those who cannot self-isolate.

The virtual-first policy and changes to access to emergency care were the most contentious measures for participants

Virtual first:

There was a general acceptance of video, online and telephone consultations in the context of Covid-19. Participants identified a range of positives relating to their own convenience, and also voiced additional selfless reasons (such as the potential to save the NHS money, and free up time for NHS staff to treat the most vulnerable patients).

Yet, there was some hesitancy towards the virtual first policy and the reduction of choice it presents. In addition to raising a number of practical concerns around the use of video, online and telephone consultations (for example, misdiagnosis or missed diagnosis, lack of rapport, lack of privacy, fraud, loss of connectivity and hacking), participants strongly felt that the virtual first approach would not work for all.

They wanted the NHS to continue to offer face-to-face appointments to people who might be disadvantaged by the policy, such as those experiencing digital access barriers and / or communication issues. They also believed it was key to measure the impact of the policy on the most vulnerable as it had the potential to exacerbate health inequalities.

Access to urgent and emergency care:

There was an agreement that the proposed measure of patients contacting 111 before attending A&E or a UTC would rely heavily on effective communications, with participants talking about the importance of educating people that A&E is not the right place to be in the majority of situations.

Participants were almost universally accepting of the principle of reducing the volume of people accessing A&E to support infection control and ensure it is available for those who most need it.

However, they raised concerns about the existing 111 service potentially being used as a triage function, mainly around its ability and capacity to cope with the increase in demand, the training of call handlers and clinicians' ability to pick up certain conditions over the phone.

In addition, in a hypothetical situation of what should happen to those attending A&E when they do not need to, on testing the idea of redirecting patients to other services, participants had a number of questions around how this would work in practice if it were to become a policy proposal.

They also voiced concerns about people 'falling through the cracks'. As such, they expected a certain amount of flexibility with regards to admitting people into A&E, particularly for vulnerable groups.

Londoners' expectations

The deliberation culminated in the development of a set of expectations in relation to the ideas and proposals discussed during the workshops. Participants were directed to develop these expectations as guiding statements that are not binding, but rather will assist the NHS when making decisions about services during the pandemic.

How participants created statements of their expectations

- Expectations (or principles) are values or beliefs and as such it is not always easy for the public to verbalise these when prompted to do so. Instead, a common technique used in deliberation is to explore participants' views around a topic, and instead to listen out for their underlying expectations in doing so. Unlike recommendations, which tend to be written by participants and framed in their own words, the draft expectations were crafted by the Ipsos MORI and ICHP team based on the synthesis of discussions from previous workshops.
- During the final workshop, the draft expectations were presented to participants and it was explained how they had been developed (i.e. through a synthesis of the discussions) and therefore that they were the research team's reflection of what participants had told them.
- In 10 groups of five to six, participants were invited to review and discuss each of the expectations in turn. Participants were asked whether they thought (1) they reflected the discussions held in their respective groups, (2) whether there was anything that should be reformulated or reworded, and (3) whether there was anything missing.
- Feedback from the 10 groups was then reviewed and each expectation was refined as result of the feedback. The final expectations were then presented to the participants and a range of senior healthcare leaders from across London at the end of the final workshop.

The following slides present these expectations.

Londoners' expectations

1. Decisions around who should be prioritised for elective procedures should be driven primarily by clinical severity of the patient. Further consideration should then be taken into account to guide decisions around prioritisation of treatment with regards to:

- Level of pain/suffering (especially for those who have been waiting longer than 52 weeks). This should be regularly assessed by the patient's clinician.
- Impact on the person's quality of life, mental health and the wider impact of delays on their ability to work.
- Caring responsibilities and overall wellbeing.
- There should be regular dialogue with people waiting longer to ensure their condition has not deteriorated.
- Patients who have been waiting over a year should be offered first refusal on cancellation slots.

Londoners' expectations

2. It is reasonable to expect that some patients may decide to delay their procedure because they are anxious about contracting Covid-19. In this situation the NHS should support the patient in the following ways:

- Every effort should be taken to inform them about the risks and implications of their choice.
- They should be given time (two to four weeks) to consider their decision whilst remaining under clinical review and be reminded as the period is coming to a close (e.g. automated text or letter).
- If they decide to go ahead with their treatment, they should return to the waiting list in a similar position to where they left it, but not at the expense of another patient’s appointment, i.e. they might return to the front of the waiting list and be in line for the next available slot.
- If they decide after the allotted time period not to undergo treatment, they should be removed from the waiting list and return to the care of their GP.

Londoners' expectations

3. It is reasonable to reduce choice of where people receive planned care in an effort to control the risk of spread of Covid-19, as long as the following conditions are in place:

- For those for whom travelling is extremely difficult and / or unaffordable, the NHS should ensure transport is provided. This should be assessed against criteria (e.g. means tested) and should be easy to book for those who meet the criteria.
- For those who may be anxious about attending a new facility for treatment, so much so that this is a barrier to treatment, the NHS should provide support to reduce this anxiety, e.g. volunteer scheme to provide a point of contact prior to the appointment to answer questions and provide additional information.
- Patients should still be able to opt to receive planned care in a place of their choice (i.e. instead of in an elective care centre), on the assumption that this might mean that they have to wait longer and that the NHS cannot guarantee a reduced risk from Covid-19.
- Patients who have very regular care needs, such as kidney dialysis or chemotherapy, should receive this closer to home to reduce the disruption of travelling further for them.

Londoners' expectations

4. It is reasonable to expect that, where possible, initial contact with patients should be virtual given the need to protect staff and other patients from potential exposure to Covid-19. However, this approach is not suitable for everyone and therefore the NHS should:

- Establish the needs and preferences of particular groups (the digitally excluded, people with language barriers, the elderly) and provide an alternative means to access health services when needed.
- Ensure that for certain consultations (e.g. those that require physical examinations, discussions around a patient’s mental health, safeguarding cases), the default should be to offer a face-to-face appointment. Certain symptom criteria need to be set out to guide this.

Londoners' expectations

5. In an effort to reduce the risk of spread of Covid-19, the NHS should restrict access to A&E and urgent treatment centres for only those who most need these services, as long as the following conditions are met:

- There must be clear and consistent messaging, widely communicated, around how to access urgent and emergency services and what to expect, to avoid the risk of confusion or deterring people from seeking help when they need it.
- The decision about who is seen in A&E / UTCs is made by a clinician (e.g. doctor, nurse, care assistant, paramedic) based on a conversation with the patient – this applies whether the patient presents at A&E or calls 111.
- If a patient presents at A&E / a UTC and it is deemed they could be more appropriately treated elsewhere, they must be directed somewhere their needs can be appropriately and quickly met (e.g. within 24 hours, or sooner if deemed as necessary) – 111 is not considered suitable as the only alternative option. There should be clear communications which state why the patient has been redirected, and what they can expect (in a way that people can understand).
- Any booked appointment should be followed by a reminder text.
- Advice, guidance and information around where to go for pain relief (e.g. pharmacy), how to manage their condition, and / or what to do if their condition deteriorates should always be provided to patients to support them whilst they wait for alternative care.
- The NHS must consider how it proactively supports everyone to access the care they need in a timely manner in light of these proposed changes, especially those groups who may be more disadvantaged by these changes.
- No one should be refused treatment.

Londoners' expectations

6. If 111 is to be used as the primary triage service for A&E / UTCs, the following conditions must be met:

- Ensure there is adequate capacity (people should not have to wait longer than 10 minutes) and clinical capability to meet the increase in demand and to support clinical assessment.
- Training for the initial call handler, particularly around mental health and care and compassion.
- People are kept informed of where they are in the queue / there is a call-back option (for people who can’t afford to hang on).
- Clear advice and guidance must be provided to those who are given appointment slots for A&E or a UTC, so that anxiety is managed as they wait at home/somewhere else.
- Patients should not have to repeat their story multiple times. Information should be available to healthcare professionals at all points along the journey from initial call to treatment (for example a reference number).
- Patients should not have to wait longer than 2 hours (or 1 hour if they are deemed as high risk, e.g. elderly, children) for a clinical call back following the initial assessment by the 111 call handler.
- 111 should be accessible to all (e.g. people speaking different languages, people with hearing impairments).

Londoners' expectations

7. It is reasonable to expect that patients should take practical steps to access services responsibly as they too have a role in controlling the risk of spread of Covid-19. For example:

- Having open and honest conversations with their healthcare professionals about whether or not they have self-isolated, or who they have been in contact with, before a procedure.
- Maintaining social distancing and good hand hygiene before coming into contact with health services. People should be informed about the importance of these measures and the risks if they don't adhere to them.
- Accessing services appropriately and in the way that they are intended to be used, for example A&E for life threatening and emergency care only*.

* While the precise wording of these expectations was informed by the deliberation and agreed among those participating, we acknowledge the removal of the word 'only' from the phrase 'A&E is for life-threatening emergencies only' in posters and on the Brent Clinical Commissioning Group website, following a complaint made to the Advertising Standards Authority.

Londoners' expectations

8. It is reasonable to expect that in making future decisions about the delivery of healthcare services, decision makers must pay consideration to the impact and implications on specific groups. This would include:

- Putting specific measures in place for those who may be adversely impacted by the decision/policy, for example transport to be provided for those for whom travelling further for treatment is more difficult and/or unaffordable.
- Measuring and monitoring the impact of decisions/policies on specific groups, for example to better understand if virtual first is limiting access to health services for those who are digitally excluded.

Methodology

A deliberation with Londoners

This report presents the findings from the second stage of a project designed to explore **Londoners' responses to the changes that the NHS is considering in response to the Covid-19 pandemic.**

This report focuses on a deliberation with Londoners, in which expectations of the NHS in the context of the pandemic were developed.

An innovative approach to developing policy in partnership with the general public

Deliberation is a progressive form of public engagement that can successfully help to shape public policy due to its ability to provide informed and considered public opinion. It convenes 'mini publics' reflective of a broader population over an extended period of time. Participants are informed by experts and supporting stimulus about the topic/s in question and then invited to explore and deliberate trade-offs associated with this.

This method creates an opportunity for decision-makers to understand public views that are carefully considered and rooted in real-life context, thus leading to more trusted and supported policy in the longer term.

Approach:

Stage 1: Dialogue

Aim: To explore Londoners' hopes, fears, concerns and expectations in relation to the measures being put in place in response to the pandemic to gather insights to inform stage 2.

Stage 2: Deliberation

Aim: Using insights gathered from the dialogue phase, explore Londoners' expectations of the mid-to longer term measures that could be put in place in response to the pandemic and the potential implications of these.

Context for the research

1. The first part of this process, the initial dialogue, took place over two virtual workshops in June. The insights gathered in the dialogue (which can be found in a separate interim report in Annex 7) reflected a high level discussion around a set of broad measures. The intention for this stage was to gather insight to expose initial reactions, concerns and tensions, which would then be used to inform the development of the second deliberative phase.

2. This report focuses on the findings from the deliberation phase of the process. Four deliberative workshops were carried out at the end of July and beginning of August. The intended output was an informed and considered set of expectations to guide future planning and further engagement at ICS level as further changes are made in the response to the pandemic. Participants were directed to develop these expectations as guiding statements that are not binding, but rather will assist the NHS when making decisions about services during the pandemic.

3. It is important to note that while the dialogue workshops were carried out during lockdown, the deliberative workshops coincided with the easing of lockdown restrictions. Despite this, participants were prepared to discuss the proposed changes in the context of a resurgence of Covid-19 cases and understood some of the challenges faced by the NHS in managing a potential second wave.

4. This engagement took place during a period where policies in response to the pandemic were forming at a rapid pace. Some proposals discussed during the process have since evolved or changed. Others were simply ideas that had not yet been formed into policies. This report sets out participant views in relation to the proposals and ideas presented to them at the time, rather than current day policies.

Approach for the deliberation

Overall approach

- Four virtual workshops were conducted over the space of two weeks, all lasting three hours. The deliberation workshops were held on Thursday 23rd, Saturday 25th, Wednesday 29th July and Monday 3rd August 2020.
- 59 participants attended all the workshops.
- In addition, a range of experts attended the workshops, providing presentations to frame the different policies, ideas and associated dilemmas that were introduced, and were available to answer participants' questions. The list of experts who attended can be found in the Annex 2.
- Alongside the main workshops, we conducted interviews and a sense-check workshop with advocates of vulnerable groups (i.e. under-represented groups and at-risk communities). In addition, 10 interviews with individuals experiencing barriers to accessing and using NHS services were carried out (see page 30 for more details).

Participants

- The participants for the initial dialogue phase were drawn from 100 Londoners who took part in the OneLondon Citizens' Summit – a previous deliberation about uses of health and care data across London. As well as being reflective of Londoners, this group was also recruited to represent a range of views towards data and digital technology.
- Drawing people from the OneLondon project meant that participants were already familiar with the deliberative process and each other therefore making the transition to virtual workshops much smoother. However, this also meant that the participants were more informed about the NHS than the 'average' general public.
- Participants were recruited across the majority of boroughs (26 in total) with quotas to ensure 11 or 12 from each STP/ICS area and to reflect the diversity of London, including ethnicity, age and socio-economic status. The profile of the participants can be found in Annex 1.

Policy areas that participants deliberated (1)

It is important to note that the measures discussed at the time of the discussions with participants were proposals rather than established policies. Since the deliberative workshops, some of the proposals have changed or further evolved. This report sets out participant views in relation to the proposals and ideas presented to them at the time, rather than current day policies. These are summarised as follows:

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To do this, some services will be consolidated to enable patients a space to be treated where the risk of Covid-19 infection is significantly reduced. We will refer to these potential changes as the consolidation of elective care.

Policy areas that participants deliberated (2)

It is important to note that the measures discussed at the time of the discussions with participants were proposals rather than established policies. Since the deliberative workshops, some of the proposals have changed or further evolved. This report sets out participant views in relation to the proposals and ideas presented to them at the time, rather than current day policies. These are summarised as follows:

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The proposals set out that those seeking urgent or emergency care would be transferred or called back by a clinical advisor; those who required it would be given an A&E/UTC appointment; and those with less severe conditions would be given remote advice or be referred somewhere else that can appropriately meet their needs.

Approach for the dialogue and deliberation

Structure of the workshops

- The workshops comprised of a combination of smaller breakout group discussions to understand and explore views and values, and whole group plenary sessions in which information was provided to the participants or where moderators would summarise findings from the smaller groups for all participants to hear.
- The smaller breakout groups comprised of five to six people. These groups were changed for every workshop and aimed to represent a mix of participant characteristics.
- The deliberation workshops aimed to cover more specific topics than those covered in the dialogue phase, and draw out principles and trade-offs. The findings in this report builds on the initial discussions from the dialogue workshops, which are contained in a separate interim report (which can be found at Annex 7).

Structure for the deliberative workshops 1 and 2

Deliberation: Workshop 1 – Prioritisation of elective care and deferring treatment

This workshop explored the concept of prioritisation in elective care given the increased numbers of patients waiting following the pandemic, and explored the following questions:

- How should we prioritise patients moving forward?
- Are there other criteria we should be considering when making decisions about who receives treatment first?
- How should the NHS respond when patients say that they want to delay their treatment until Covid-19 is less of a risk?

The workshop comprised plenary discussions with experts introducing the notion of prioritisation in elective care, followed by smaller breakout group discussions and exercises that pushed participants to make decisions and start formulating principles on prioritisation. In addition to the presentations, stimulus included exercises involving fictional patients and their conditions, which participants were asked to place in order of who they thought should receive treatment first and why.

Deliberation: Workshop 2 – Access to planned care

This workshop explored some proposed changes to NHS services around access to planned care in the context of the pandemic. Discussions focused on the consolidation of elective services, the virtual first and the self-isolation policies.

It explored the following questions:

- What would make the reduction of choice in where / how people receive their care more acceptable, given that there is a pandemic?
- What would make the reduction of choice that the virtual first approach presents (in not being able initially to see someone face-to-face) more acceptable?
- What are participants' expectations of how the NHS manages self-isolation for a range of different situations?

The workshop comprised plenary discussions and breakout group discussions. Stimulus materials included presentations from experts, handouts to demonstrate the proposed changes and case studies illustrating how the changes might impact on individuals both positively and negatively.

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Structure for the deliberative workshops 3 and 4

Deliberation: Workshop 3 – Access to emergency and urgent care

This workshop explored the proposed changes to emergency and urgent care access in response to the Covid-19 pandemic. It explored the following questions:

- How do people feel about limiting walk-in access to A&E and re-directing people to other services?
- How do people feel about 111 as an initial triage service?
- Who might this work well for and who might it work less well for?
- What would make these potential changes more or less acceptable?

The workshop comprised whole group discussions about urgent and emergency care. There were several breakout group discussions exploring these emergency care options and how they might affect different patients. Stimulus for this included one presentation highlighting the rising demand for emergency care services (following a significant reduction in demand during the height of the pandemic), another describing the planned changes, fictional scenarios and patient journeys.

Deliberation: Workshop 4 – Finalising expectations and communications

The final workshop had two aims:

1. Invite participants to reflect on and refine the emerging expectations about how proposed changes in response to the pandemic should be developed.
2. Invite participants to reflect on what the key messages around the proposed changes should be, and how people could be kept informed of those emerging policies.

This comprised predominantly of breakout group discussions to reflect upon and refine the expectations that had emerged from the findings from the previous workshops. Participants were introduced to these in a plenary presentation and then discussed them at length in the smaller groups, before a final plenary discussion to present the final expectations to the wider group. Participants were directed to view the expectations as guidance for the NHS, rather than binding statements. The stimulus for this included the eight expectations developed following analysis of the initial three workshops and a presentation summarising the key emerging findings. There were also breakout discussions on communications

Gathering enhanced insights from under-represented groups and vulnerable communities

Overview of objectives

The cohort for the dialogue and deliberation process was recruited from a group designed to reflect the diversity of London, including by ethnicity, age and socio-economic status. However, to ensure the voices of people likely to be under-represented in the cohort due to access issues (digital or societal), additional engagement was carried out to enhance our understanding of their views and perspectives on the proposals and ideas. The engagement was three-fold:

1. Interviews with advocacy groups

We spoke to a range of advocacy groups who helped to provide insight from across specific populations who may have been disproportionately impacted by 1) the virus itself; and / or 2) measures put in place to address it.

This included groups representing people with specific medical needs and / or vulnerable communities (a full list of organisations is included in Annex 4).

2. Interviews with people with lived experiences

Before the deliberative workshops, we carried out ten in-depth interviews with people with lived experiences (including homeless people, people with learning disabilities, a Traveller, and a patient with a mental health condition).

The interviews focused on their experiences of accessing and using services, and early thoughts on the proposed measures.

3. Sense-check workshop with advocacy groups

We carried out a sense-check workshop where a number of advocacy groups were invited to reflect on participants' expectations (a full list of groups is included in Annex 4).

This was carried out to ensure that any additional and / or different considerations informed by the views and perspectives of those advocating for under-represented groups and vulnerable communities could be reflected in the final report presented to decision makers.

In addition to actively engaging these groups, workshop participants were exposed to their voices, fears, and hopes, and what the proposed measures might mean for them throughout the deliberation.

How participants created statements of their expectations

Expectations (or principles) are values or beliefs and as such it is not always easy for the public to verbalise these when prompted to do so. Instead, a common technique used in deliberation is to explore participants' views around a topic, and listen out for their underlying expectations in doing so.

Unlike recommendations, which tend to be written by participants and framed in their own words, the expectations were crafted by the Ipsos MORI and ICHP team.

During the final workshop, the generated expectations were presented back to participants.

In doing so, it was explained to participants how the expectations had been generated (i.e. through a synthesis of findings in the previous workshops) and that they were the research team's reflection of what participants told them.

Each of the ten groups were encouraged to discuss the expectations in turn.

Participants were asked whether they thought (1) they reflected the discussions held in their respective groups, (2) they should be reformulated or reworded, and (3) whether there was anything missing.

Each expectation was then refined and presented back to the participants at the end of the fourth and final workshop.

How to read this report (1)

1. **This report focuses on findings from a deliberation with Londoners**, which took place across four virtual three-hour workshops. This series of deliberative workshops were the subsequent phase of the initial dialogue that took place across two virtual workshops with the same Londoners.

   The dialogue phase of the programme was intentionally used to bring Londoners up to speed on some of the ways that the NHS has responded to the Covid-19 pandemic, and may respond in the future, and seek initial reactions to these.

   This second deliberative phase of the programme **worked with the same participants to explore in more detail the real life dilemmas that decision makers are faced with** and the **associated trade-offs, to develop a set of expectations** that can guide future decision-making in the context of responding to the pandemic (though not be binding).

2. **Deliberative findings are used to shed light on why people hold particular views** rather than how many people hold those views. We can be confident that the principles and views presented in this report are **credible and valid** due to the following strategies used in this deliberation: **accounting for bias, meticulous record keeping and systematic analysis, validation and data triangulation**.

   The culmination is this report, which provides detailed and nuanced evidence on how participants' views, concerns, aspirations and expectations can be used to inform future emerging plans for the NHS as it enters the next phase of the pandemic response.

3. **This report uses the conventions of qualitative social science reporting:** An indication via "a few" or "a limited number" to reflect views which were mentioned infrequently, and "many" or "most" when views are more frequently expressed.

   The use of "some" reflects the balance between these – views which were mentioned by some participants, i.e. more than a few but not by a majority of participants. This report focuses on perceptions rather than facts and any proportions used in the reporting should be considered indicative, rather than exact.

How to read this report (2)

4. **Findings from the targeted engagement with advocacy groups and interviews with people with lived experiences are included in this report**. The additional considerations for under-represented and vulnerable groups, presented in this report after each expectation, are derived from a workshop held with a range of advocacy groups that reviewed Londoners' expectations.

5. **Finally, this report focuses almost entirely on NHS services**. This is not to say that significant changes have not occurred across the care sector too, however, the topics being discussed during the deliberative phase related solely to NHS services where the policy dilemmas are much clearer.

Prioritisation in planned care

What participants discussed about prioritisation of elective care

Participants were informed about how the capacity available to provide elective treatment has always been limited due to both operating theatre space and the number of skilled staff available (including use of the private sector) and is now even more so due to infection control measures.

It was also explained that historically the NHS has broadly prioritised elective procedures according to how long someone has been waiting.

During the early stages of the pandemic, a framework developed by the Royal College of Surgeons (see below) had been used to prioritise procedures on the basis of clinical severity.

Throughout the discussion participants were asked to reflect on the following:

- How should the NHS prioritise patients moving forwards? What factors should be taken into consideration and why?
- Are there other criteria we should be considering when making decisions about who receives treatment first?

Cat.	Description	Example
1a	Requires surgery within 24 hours	Patient has chest pain due to a blocked artery
1b	Requires surgery within 72 hours	Patient has appendicitis and needs to have appendix removed
2	Requires surgery within a month as condition may deteriorate	Patient has a spinal injury that is damaging the nerves; this could lead to permanent damage if not treated quickly
3	Requires surgery within 3 months	Patient has recurrent bleeding caused by varicose veins and requires vascular surgery to address this
4	Clinically safe to wait longer than 3 months	Patient has fibroids and requires a hysterectomy

The need for prioritising was generally accepted, although with concern for individual patients affected

1. Patients were concerned about the length of waits, though generally accepted the need to prioritise patient lists:

When hearing about the length of time that some people in London are currently waiting for treatment, this caused some concern amongst participants.

However, given the circumstances of the pandemic and the impact it has had on the ability of the NHS to treat patients, there was a recognition that the NHS cannot treat everyone at once. In the context of Covid-19, participants therefore generally understood the need to prioritise waiting lists.

> “*I just think that it’s just going to have to be a case of some really tough, horrible decisions are going to have to be made, it’s going to be tough but it’s the world that we’re in right now.”*
>
> **(Male from Hammersmith & Fulham).**

> “*This seems quite clinical and easily prioritised with minimal bits of information but it’s just the surface and a lot more to be looked at with lockdown...*
>
> *Behind all of these figures are people and their stories and their individual circumstances that may move them up and down [the list].”*
>
> **(Female from Enfield).**

2. Participants wanted to consider a range of information about each individual patient:

Overall, participants were reaching for more information than simply the clinical severity of the patients’ conditions, their length of wait and their age. They thought it was important to consider a person and their circumstances in the round.

3. The process of prioritising a list of patients was challenging:

Participants thought about the patients and their circumstances, and also the NHS staff having to make decisions, and recognised that these were very difficult decisions.

Clinical severity was seen as a key factor for driving prioritisation decisions

Clinical severity was the over-riding factor that should be taken into account when deciding the order in which to prioritise patients: Participants had been introduced to a framework developed by the Royal College of Surgeons (RCS) that categorised different procedures according to their clinical severity. This was central to how participants determined the higher priority patients for treatment.

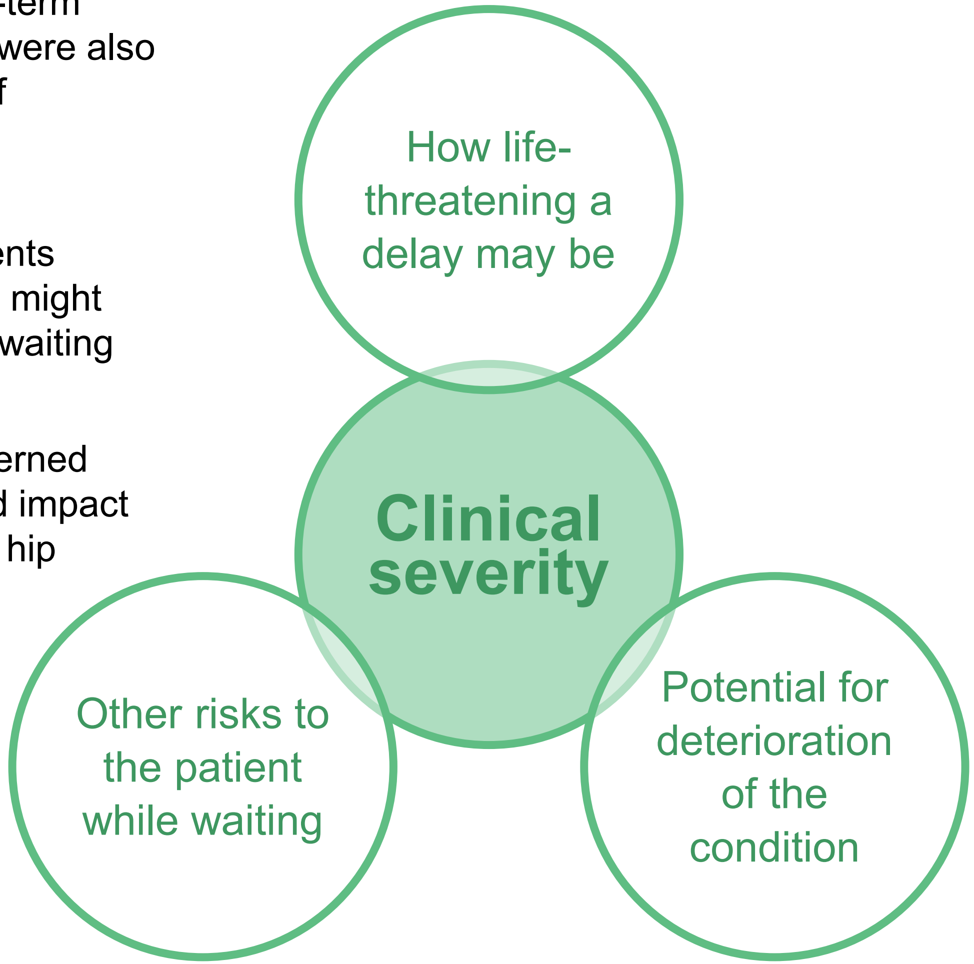
As part of judging clinical severity, participants discussed other features of severity: In addition to the RCS framework, there were further considerations linked to clinical severity that participants thought should be taken into account around the impact of waiting.

Life-threatening: A key part of clinical severity for participants was the risk to life of delay (e.g. the risk of heart attack).

Potential deterioration: The longer-term impacts, even if not life-threatening, were also important (e.g. the risk of blindness if cataracts are not removed).

Linked to this, some concerns were specifically raised about elderly patients whose conditions and independence might rapidly and irreversibly deteriorate if waiting for treatment too long.

Other risks: Participants were concerned about other consequences that could impact clinically (e.g. someone waiting for a hip replacement having a fall).



How life-threatening a delay may be

Clinical severity

Other risks to the patient while waiting

Potential for deterioration of the condition

Level of pain, quality of life and age – while not as important as clinical severity – were also key factors

Participants raised three interlinking factors as being important – level of pain, quality of life and age:

Alongside clinical severity, these three factors frequently emerged as being important considerations when prioritising waiting lists. It was often not possible for participants to separate out these interlinking factors.

Level of pain:

Participants spontaneously raised concerns about the level of pain a patient was in while they waited for treatment. They thought this should be considered, especially for patients who had been waiting longest for treatment. They recognised, however, that different people have different pain thresholds.

> *Pain is very important. Now patient J should be high as they are in severe pain, it doesn't matter how long they have been waiting."*
>
> **(Female from Waltham Forest).**

Quality of life:

The level of pain was closely linked to quality of life, as participants thought that patients experiencing severe pain would also have a poorer quality of life. Quality of life also referred to the broader impact of a condition on the patient's life, for example their ability to do daily activities.

> *The key thing for me is how much it interferes with someone's life… We need an objective measure, to say what the probability of having a debilitating effect on someone's life and how long we should let this impact someone's life."*
>
> **(Male from Southwark).**

Age:

A patient's age was also an important factor for many participants. With the specific examples provided, this was related to quality of life and the various risks of delaying treatment for older people. Others also thought children should be prioritised as they would be more likely to recover quickly.

> *My first thought was to prioritise the older person first, because they may be having other problems as well with their health, but again, it's difficult to say without really knowing what the procedures are and what their lifestyles are or conditions are."*
>
> **(Male from Barnet).**

Participants also thought wider factors about patients' lives were important, beyond more clinical considerations

The patient's circumstances, in terms of whether or not they had dependants, was very important to participants:

These circumstances, for example if the patient had children to care for or support financially and if the patient had a partner to care for, were as important to participants as the patient's level of pain, quality of life or age.

> *If you have to make a decision who the next person is in the bed, the person who has people relying on them needs to be first."* **(Male from Southwark).**

The extent to which a patient would be cared for was also important, albeit a less important consideration than having dependants:

The amount of care a patient needs and has access to before and after their treatment was also an important consideration for participants, although this was less prominent than whether the patient was supporting or caring for dependants.

> *We forget about the social care support network in the context of how vulnerable that person would be, are they living by themselves or do they have a strong family support network?"* **(Male from Brent).**

There were other secondary considerations not linked directly to the more clinical considerations:

These factors were less important than clinical severity, level of pain, quality of life, age and whether the patient has dependants. Factors included:

The impact on the patient's **mental health:**

> *Mental health can exacerbate, especially if you have anxiety everything seems worse and it will bring it up a notch in terms of severity."* **(Male from Richmond).**

The patient's **employment and financial status**:

> *If there were three cases and all identical and one person was in more financial hardship, it would be nice to think that that person gets prioritised. The health should be the priority in the choices, but with equal stances, that would be a humane thing to do."* **(Female from Islington).**

The length of wait was generally less important in itself, although it could impact on other key considerations

The length of wait was important insofar as it affected the other considerations, rather than in its own right:

This is because it would affect a range of factors that participants thought were important when prioritising patients on a waiting list. For example:

- Over time, patients' conditions may deteriorate, leading both to worse outcomes for the patient and potentially additional cost to the NHS.
- The longer a patient waits, the greater the other risks (e.g. a fall).
- While a patient's quality of life may be acceptable for a fixed period of time, if quality of life is impaired over longer periods this could impact more widely on the patient's ability to support and care for dependants, and the patient's mental health and financial wellbeing.

> “*If you've been waiting for a year with that level of discomfort and pain, that can be very debilitating and have a knock-on effect on mental health.*” (**Female from Barking & Dagenham).**

As a result, some thought that the length of wait should be capped, so it does not go above a certain length:

A minority of groups concluded that, once a patient had a lengthy wait (for example, one year), they should be prioritised (regardless of clinical severity).

Summary: participants created a statement of their expectations for policy makers (1)

1. Decisions around who should be prioritised for elective procedures should be driven primarily by clinical severity of the patient. Further consideration should then be taken into account to guide decisions around prioritisation of treatment with regards to:

- Level of pain/suffering (especially for those who have been waiting longer than 52 weeks). This should be regularly assessed by the patient’s clinician.
- Impact on the person’s quality of life, mental health and the wider impact of delays on their ability to work.
- Caring responsibilities and overall wellbeing.
- There should be regular dialogue with people waiting longer to ensure their condition has not deteriorated.
- Patients who have been waiting over a year should be offered first refusal on cancellation slots.

Additional considerations in relation to under-represented and vulnerable groups (1)

The workshop with advocacy groups emphasised the following points:

- Patients need transparency regarding waiting times and clarity around where they are in the pathway.
- Advocacy groups agreed on the need to include patients’ individual circumstances in decisions around prioritisation. Doing so would mean more personalised care and could help foster shared decision-making between a patient, their clinician, and their carer(s).
- In addition to whether someone has caring responsibilities, decisions around prioritisation need to consider the potential impact of delaying treatment on a patient’s carer, for example how this could affect their wellbeing, financial status and quality of life.
- It is critical to provide reassurance to patients on what will happen when they go to hospital – people might be fearful or intimidated. Videos, pictures and clear explanations need to be provided so patients know what to expect before an elective procedure.

Deferring treatment

What participants discussed about deferring treatment

Participants were informed that during the pandemic, some patients who have been scheduled to come into a hospital to receive their planned treatment have requested to delay their procedure until Covid-19 is less of a risk. The NHS needs to manage these situations with patients to ensure that they are not put at more risk because of their condition from delaying their treatments.

It was explained that some areas of the NHS in London were trying different approaches to deal with this issue, and participants were presented with one of these potential approaches (see Annex 5). They were then asked to reflect on the following questions:

- How acceptable do you find it that people might want to refuse treatment?
- What should happen if people choose to delay treatment? What is your expectation of how the NHS should respond?

Participants emphasised the importance of informed choice when patients make decisions about their treatment

Many participants could understand why patients may be fearful of attending hospital for treatment given the pandemic:

There was sympathy for people who were due to have treatment but were fearful of Covid-19.

> *I'm looking at the fact I'm BAME, so many people I know going into hospital and not coming out as a result of Covid-19. I would be thinking a lot about that.”* **(Female from Croydon).**

There were some concerns about more vulnerable groups:

It was important for some participants for GPs to establish if a patient has the mental capacity to make an informed choice.

> *To add to that, mental capacity comes into play, if they have it then they have the right to decline because they have the mental capacity to do this, but if they don’t have mental capacity then your best interest comes into play like learning difficulties, like dementia that’s not controlled, so then a decision would have to be made on behalf of them.”*
>
> **(Female from Merton).**

Participants emphasised the importance of patients making informed choices about their treatment:

Although some thought that patients should go ahead and have their treatments, in general participants thought that patients should be given the information they need to make an informed choice about their treatment. This would require a GP or consultant having a one-to-one discussion with the patient in which the risks and consequences associated with the decision are clearly communicated.

> *It’s the decision of the patient and you have to respect their choice, but having a doctor emphasising that the cons of the condition and implications of their health really needs to be laid out for them. After listening to all of that if they are still adamant to put it on hold then they can, you have to respect it.”*
>
> **(Female from Kensington & Chelsea).**

A cooling-off period was widely supported, but conditions were attached to ensure the system is fair and efficient

To help patients to make an informed choice, participants broadly supported the idea of a cooling-off period:

The cooling-off period was mainly discussed in the context of patients declining treatment due to fear of contracting Covid-19. It was perceived to give the patient time to speak to clinicians and consider their decision without being penalised, i.e. they would go back on the waiting list at the same point as when they entered the cooling-off period.

However, they thought that a two or four-week period was sufficient to consider for patients to consider their decision (as opposed to the proposed 8 week period).

Yet, there were widespread concerns about the implications of the cooling-off period:

Conditions were attached to any system addressing patients wishing to delay treatment due to fear of Covid-19.

In response to these concerns, participants thought that a cooling-off period of 4-8 weeks would be sufficient, and were comfortable with patients being removed from the waiting list following their cooling-off period.

The impact of a patient delaying treatment on other patients was a key consideration:

While understanding why patients may wish to delay and generally supporting their right to consider their treatment, participants thought this should not impact on other patients on the waiting list, emphasising fairness.

> “*I think the key is that their decision doesn’t impede on someone else who wants to get their treatment. I think that would be a consideration that I would like to make sure that someone else isn’t adversely affected.*”
>
> **(Female from Barking & Dagenham).**

There were also concerns about the impact of a cooling-off period on the NHS:

Some participants questioned the impact on the efficiency of the NHS in managing waiting lists, and the impact on clinicians needing to take time to speak to patients who are concerned about treatment

> “*I'm just looking at all of this and thinking of a stretched NHS, and all the extra admin and phone calls that need doing for all this stuff and how it clogs up the system more.*”
>
> **(Male from Enfield).**

Summary: participants created a statement of their expectations for policy makers (2)

2. It is reasonable to expect that some patients may decide to delay their procedure because they are anxious about contracting Covid-19. In this situation the NHS should support the patient in the following ways:

- Every effort should be taken to inform them about the risks and implications of their choice.
- They should be given time (two to four weeks) to consider their decision whilst remaining under clinical review and be reminded as the period is coming to a close (e.g. automated text or letter).
- If they decide to go ahead with their treatment, they should return to the waiting list in a similar position to where they left it, but not at the expense of another patient's appointment, i.e. they might return to the front of the waiting list and be in line for the next available slot.
- If they decide after the allotted time period not to undergo treatment, they should be removed from the waiting list and return to the care of their GP.

Additional considerations in relation to under-represented and vulnerable groups (2)

The workshop with advocacy groups emphasised the following points:

- The need for transparency around risks (of catching Covid-19 and delaying treatment) is critical, so patients can make fully informed decisions around whether to delay treatment or not.
- It is important to understand people's own perceptions of risk so reassurance can be provided – some individuals or communities might be more nervous about being exposed to Covid-19 than others.
- Linked to the need for reassurance, people also need to be kept informed of the risks of infection and risk mitigation measures put in place in the event of a second wave (for instance, through local and tailored communications).
- Certain vulnerable individuals or groups might need more time than two to four weeks to decide whether they want to go ahead treatment or not. The cooling-off period needs to be flexible.

Consolidation of elective care services

What participants discussed about consolidation of elective care services

Participants were informed that some elective services may be consolidated in an effort to reduce the risk of infection. Additionally they heard that there is evidence to suggest that undertaking similar procedures in the same place means that more can be performed each day, increasing how many people can be treated and therefore helping to address the backlog. This could include creating designated ‘clean spaces’ for:

Elective care centres

Focused on specific treatments such as hip replacements

Diagnostic hubs

Bringing together key diagnostic services such as CT scanning or endoscopy into one place

Throughout the workshop, participants were presented with a range of stimulus materials and exercises and asked to reflect on the acceptability of a potential reduction of choice in where / how people receive care in the context of a pandemic.

For most, the consolidation of elective care services was welcomed, with the positives clearly outweighing the negatives

The consolidation of services (elective centres and diagnostic hubs) in response to the pandemic was well received, and for most the pros outweighed the cons:

There was some awareness of specialist centres, with mentions of Great Ormond Street Hospital, The Royal Marsden and Moorfields. There were participants who viewed the consolidation of services as a positive move, even in the absence of Covid-19.

> *I think if coronavirus hadn't happened, these are good things which will reduce the waiting time. That's the major thing, waiting times. If you have a team that are just dealing with this, I think it can help the waiting time go down. I think post-Covid-19, this new way of working would be good."*
> **(Male from Westminster).**

Key positives, aside from reducing the backlog in waiting lists, which were often perceived to be interlinked, included:

Safety from Covid-19 - especially the case for those who were worried about accessing services (though some questioned the feasibility of keeping centres Covid-19-free).

> *I think it is a good idea to have a centre that deals with one specific health aspect. It is streamlined, more efficient, faster. There will be the right members of staff in that field of area. I can see the plus side."* **(Female from Lambeth).**

Efficiency - in terms of staffing, taking pressure away from big acute hospitals, patients being seen quicker and less chance of procedures being cancelled or staff being needed in A&E.

> *I think in principle it sounds like a good idea. No one there will have Covid-19. There's no risk. You'll get it quicker than if you went to a local hospital. It depends on if you can travel."* **(Female from Harrow).**

Access to the right care - there was an expectation that care would be streamlined and of a higher quality to that which a patient might receive in their local hospital.

Generally, participants were willing to compromise on choice, while recognising the importance of still offering it

A discussion about choice was situated in the current pandemic, alongside a desire for patients to receive the best possible care available to them.

Participants mentioned the recent **removal of choice in society more widely** (having to wear face masks, change to the way we are living our lives), which made the removal of choice here more acceptable.

> *It has to be acceptable. Our everyday lives, it's not just visiting hospitals or operations or procedures, everything in our lives has changed and we just have to go with it. So people have to accept this is the new way of doing things."*
>
> **(Female from Redbridge).**

There was also, for some, a sense that **choice is less of a factor** given that specialist centres were perceived to be the best places for patients to receive their care.

> *If someone had a serious brain injury, they might go to a particular hospital, heart trouble to another one. If you're in that position, you don't really care where you go, you're just happy to get the treatment."*
>
> **(Female from Bromley).**

A minority view was that too much choice is burdensome for patients. But it was clear, across the board, that choice is more important for people in vulnerable circumstances (for example those with physical disabilities, or anxiety about going somewhere unfamiliar). Participants concluded that it will be necessary for the NHS to facilitate choice, while being clear about the implications of each option.

> *This service centre would be better care for you, but if you want to go to a local hospital, the only negative is longer waiting, and that we can't guarantee your time or date. I think we should be offered a second choice and told that you have to go to that hospital, you'll have better service and better care, but if you want to go to local, okay."*
>
> **(Male from Barnet).**

Though a major caveat of moving towards consolidation was the need to provide additional support to those who will need it

The necessity of patients potentially having to travel further to receive care in an elective centre, or a diagnostic hub, was understood by all:

However, while the majority of participants indicated willingness to sacrifice travelling further if they needed a procedure given the pandemic, they also recognised that this would not be a straightforward compromise for everyone.

> *The consolidation of walk-in services is already happening. It's more complex when it comes to treatment, like needing a serious operation and having to travel further, I'm willing to do so but some people will have difficulties and it will be a stressful experience for them."* **(Male from Enfield).**

> *I would be happy as long as you can mitigate for those who have difficulty about travelling."* **(Male from Barnet).**

Participants were clear that the NHS will need to provide support to people for a range of reasons:

These included organising travel for those who most need it and support for patients with anxiety induced by receiving care in an unfamiliar environment or with a different consultant (continuity of care was important here, especially for people with mental health needs).

> *If vulnerable people need to travel and go to new places that can be daunting. So there needs to be one person to help with anxieties. I suffer with anxiety and if I need to go somewhere new it doubles the anxiety and stops me going. If that's sorted for people who are vulnerable and anxious it's a good idea."* **(Female from Bexley).**

> *I think the patient needs to be looked [at] holistically. If the patient is low-income, doesn't drive, or is vulnerable, for example, I think that those measures do need to put in place to make sure that the patient is given the proper care."* **(Female from Merton).**

The risk of widening existing inequalities was highlighted, as well as the impact on those receiving regular care

Participants flagged the risk that people who are already vulnerable may be further disadvantaged.

> *The main problem is it disadvantages those who are already disadvantaged, those without access to transport and those with other complications can't be treated as quickly. It's divisive although it does seem a good idea."*
> **(Male from Richmond).**

However, when discussing the provision of patient transport for those who may need it, **some were conscious of NHS resources** and thought there should be some form of means-testing (as at present, although participants were generally not aware of this).

> *The elderly, [people with] underlying health issues. It's hard because you can't give everyone free transport, but it has to be narrowed down."* **(Female from Redbridge).**

And a clear red-line was the requirement for those needing regular care to travel further:

for example patients receiving chemotherapy or kidney dialysis. Participants were clear that they would need to be offered treatment closer to home.

> *It would get annoying if it was regular. If you had cancer treatment for example. If a lot of time is on travelling. But it could be closer to you and work out better."* **(Male from Brent).**

This linked to a suggestion for the NHS to consider where elective centres are located:

based on local demographics and clusters of certain conditions. There was also the occasional suggestion for mobile diagnostic units.

The importance of patients' medical records travelling with them was occasionally mentioned.

> *Have they got all your notes in case you forget you're allergic to penicillin or something like that?"* **(Female from Harrow).**

Perspectives from under-represented groups and vulnerable communities

Similarly to the workshop participants, the people with lived experiences we talked to agreed that the consolidation of elective services was a sensible way of trying reduce transmission of Covid-19.

However, there were concerns around the difficulties this could pose for some people:
for example those who may be capable of travelling to their local GP or hospital but may find travelling further afield more distressing, or would need someone to accompany them (e.g. for people with learning disabilities or mental health issues).

> *For people with mental health issues, being taken to a hospital which is far away from their area and their families and friends, it's a big thing for them, especially if they're having an episode, it can add to the paranoia and it can take longer for them to being well again… If you're becoming unwell, you need to have that sort of consistency of who's caring for you."* **(Female, bipolar).**

> *It would feel too upsetting [to travel to a further hospital]."*
> **(Female with learning disability).**

Participants were keen to emphasise the importance of continuity of care in that context.

Summary: participants created a statement of their expectations for policy makers (3)

3. It is reasonable to reduce choice of where people receive planned care in an effort to control the risk of spread of Covid-19, as long as the following conditions are in place:

- For those for whom travelling is extremely difficult and / or unaffordable, the NHS should ensure transport is provided. This should be assessed against criteria (e.g. means tested) and should be easy to book for those who meet the criteria.
- For those who may be anxious about attending a new facility for treatment, so much so that this is a barrier to treatment, the NHS should provide support to reduce this anxiety, e.g. volunteer scheme to provide a point of contact prior to the appointment to answer questions and provide additional information.
- Patients should still be able to opt to receive planned care in a place of their choice (i.e. instead of in an elective care centre), on the assumption that this might mean that they have to wait longer and that the NHS cannot guarantee a reduced risk from Covid-19.
- Patients who have very regular care needs, such as kidney dialysis or chemotherapy, should receive this closer to home to reduce the disruption of travelling further for them.

Additional considerations in relation to under-represented and vulnerable groups (3)

Advocacy groups who took part in the workshop were supportive overall of the consolidation of services (elective centres and diagnostic hubs) in response to the pandemic but emphasised the following points:

- Patients need to be talked through the different options they have. Different types of choice matter to different people.
- Linked to this, NHS staff should not make assumptions about individuals' trade-offs and risk perceptions: some people might be willing go anywhere for an elective procedure, others might not.
- This measure could exacerbate health inequalities for those who decide to wait in order to get treatment closer to where they live if this was an option available.

The 14-day self-isolation standard

The 14-day self-isolation standard seemed sensible for those who are able to, but unrealistic for many

- At the time of the workshop, the 14-day self-isolation national standard prior to a procedure was in place for infection prevention during a period of high Covid-19 community transmission, and was deliberated as it was identified as an area of tension in the dialogue.

- Since the workshop, the guidance on self-isolation has changed and patients having an operation or treatment on the NHS no longer need to self-isolate for 14 days prior to this unless they are in groups considered more vulnerable. Instead, updated guidance advises strict social distancing and hand washing in order to reduce the risk of spread of infection.

In early discussions the requirement for patients to self-isolate before a procedure was perceived as sensible and necessary: some went as far as to suggest that people who have not self-isolated should be refused treatment and return to the waiting list.

However, it became clear that the 14-day standard was unrealistic: as discussions progressed and participants were introduced to several case studies, which portrayed people in different personal situations, participants began to think it was not practical for many.

> “*If it’s just two people that are retired, then it’s probably slightly different, but for millions of people, it just doesn’t work like that.”*
> **(Female from Kingston upon Thames).**

Participants had major concerns about the financial implications for those who would not be able to work if they self-isolated for 14 days. Similar concerns were raised for the self-employed, students, people who live alone (lack of support systems, anxiety and loneliness), people who live with others (the impact on other household members) and those requiring regular treatment. The debate became one about fairness and human rights.

> “*I think the 14 days is an awful long time for someone like myself who lives by myself, but for families it’s really impossible because you’ve got the husband, wife, a number of children, they have to isolate themselves with no money coming in. It’s virtually impossible.”*
> **(Male from Enfield).**

> “*I don’t think it's feasible to have one rule for everyone. Like I said, my girlfriend’s dad has to go hospital 3 times a week for dialysis so it's not possible for him.”*
> **(Male from Newham).**

They thought that the NHS in London should have a single policy to ensure consistency and fairness in the requirement for self-isolation across the Capital.

The standard will be impossible to 'police', so the NHS should plan as though no-one has self-isolated

Participants recognised that there will be people who do not self-isolate, and also those who believe that they have protected themselves from the virus but contract it on public transport while travelling to the hospital:

The difficulty of policing and proving that patients are infection free was consistently noted, even with testing in place. As such, participants suggested that the NHS should assume that no-one has self-isolated.

> *Maybe the NHS needs to assume no one is going to do that and for every procedure, you need to have PPE. Ask them to, but presume that they're not."* **(Female from Bexley).**

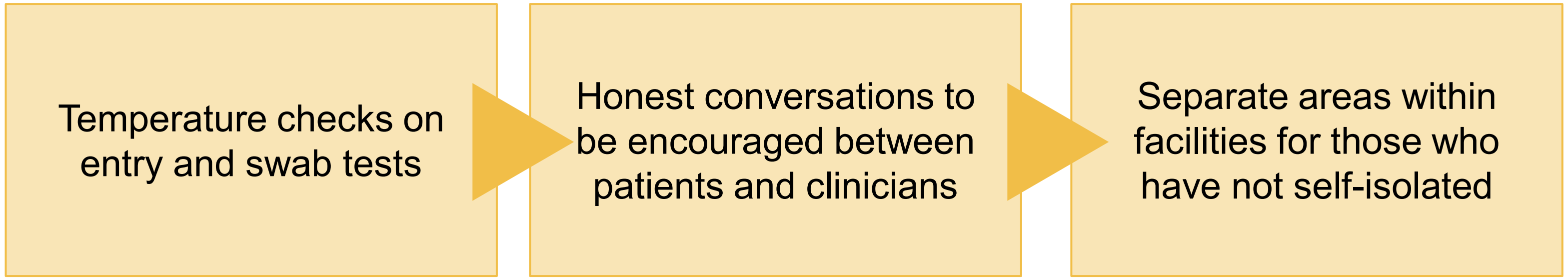
If the NHS is going to enforce this standard, participants felt it was imperative that financial support is offered to patients who would need to take time off work.

They looked to the government to provide this.

> *A mini furlough for medical needs, to allow them to have the procedures and come back. It's terrible. But how quickly did they do the furlough system.*
>
> *There are people who just can't take the time off, it's an impossible situation."* **(Female from Sutton).**

Clear guidance and instructions about what people should and should not be doing before a procedure was also called for.

Participants quickly moved on to make suggestions for alternatives to the 14-day self-isolation standard, and there was confusion around why the NHS can't just test people as they arrive.



Temperature checks on entry and swab tests

Honest conversations to be encouraged between patients and clinicians

Separate areas within facilities for those who have not self-isolated

Perspectives from under-represented groups and vulnerable communities

At the time of the interviews, due to high levels of community transmission of Covid-19, the guidance was for people to self-isolate for 14 days prior to a procedure. Under-represented and vulnerable participants understood the rationale behind this.

However, they also worried about how some people would not be able to follow the guidance, and how some may suffer from following it:

People with mental health conditions

> *This might be too much for them, but if you had some kind of assessment of their mental health and to make sure someone was able to check in with them over that time."*
>
> **(Female, bipolar).**

People with learning disabilities who might not only suffer from being isolated but might also struggle with practical tasks such as online shopping and banking.

> *It would be awful really, back to having to stay indoors… I'm not very good at online shopping so I would have to rely on the LD [learning disability] team."*
>
> **(Male with learning disability).**

People experiencing homelessness, who might not to able to find a place where they can self-isolate. And if they did, they may not then have access to services such as foodbanks.

> *They might try to follow it as best they can, but practically they can't, I don't think it's reasonable to ask street homeless people to self-isolate for 2 weeks."*
>
> **(Male, homeless advocate).**

Virtual first

There was a general acceptance of virtual consultations and participants felt this was an inevitable way forward for the NHS

Participants were informed that, in an effort to reduce the spread of infection, initial contact with the health service would be virtual where possible and appropriate.

Various examples were provided, and participants were also presented with the main themes that had emerged from the discussions around virtual appointments during the dialogue workshops (see Annex 6).

Across all groups, participants agreed that the pandemic had meant that video, online and telephone consultations had become a new normal:

Out of all the measures discussed, this is the one participants felt was the most likely to carry on after the pandemic.

> *Covid-19 has generated it, but [the shift to virtual consultations] is the future.”* **(Female from Bromley).**

Participants were largely positive about the use of virtual consultations generally during the pandemic, citing reduced risk of exposure to Covid-19 (by avoiding travelling to their appointments and also waiting on site to be seen).

However, there were disagreements about whether the virtual first policy was acceptable for outpatient appointments in particular. Some thought that although they could envisage it working for GP appointments, because of familiarity, this was less acceptable for appointments with clinicians they had not met or talked to before. In this instance, a pre-existing relationship was deemed crucial.

> *think even if people do have the technology, speaking face-to-face on a screen, I’ve not experienced having to speak to my GP like this, but maybe having to speak to a consultant who you’ve not met before on a screen like this might be intimidating to some people, they may not like it.”* **(Male from Enfield).**

However, there was some hesitancy around the virtual first policy, with participants less ready to accept the reduction of choice it presents

The development of video, online and telephone consultations as a result of the pandemic was welcomed by most participants:

They listed a number of advantages relating to their own convenience, even if they did not guarantee continuity of care. They also mentioned additional selfless reasons such as the potential to save the NHS money, and free up some time for NHS staff to treat the most vulnerable patients.

> *The fact that they can see the bulk of people this way probably means some GP time can be freed up to see more vulnerable people or those without access or without technology. They might be able to see them personally."*
>
> **(Female from Lambeth).**

Despite the wide consensus that video, online and telephone consultations had many advantages and were suitable for most, there was some disagreement among groups on whether the virtual first policy – and the reduction of choice it presents – was acceptable.

Some were supportive and argued that virtual consultations could stop people requesting face-to-face consultations when they didn't really need it. Others still wanted to have the ultimate say in the type of appointment they were offered – even though they agreed that video, online and telephone consultations were adequate for most, and in most cases. They felt that they were well placed to know if their condition or circumstances meant that they needed to be seen face-to-face.

There were also some practical concerns and questions raised around the use of video, online and telephone consultations

Participants raised a number of major concerns around video, online and telephone consultations:

Misdiagnosis or missed diagnosis: this was the main concern discussed. Participants noted the difficulties of diagnosing certain conditions virtually.

To mitigate the risks associated with this, a number of suggestions were made:

- How patients could be entitled to an annual face-to-face 'check-up' with their GPs (awareness of the NHS Health Check for adults aged 40-74 appeared to be low).
- How clinicians should receive additional training to learn how to communicate remotely in video, online and telephone consultations to ensure they and their patients get the most out of them.
- How email communications from and to their clinicians would be helpful. This would provide the opportunity to add relevant information after an appointment if needed, and time to read and reflect on what clinicians had said.

Lack of rapport: concerns about the loss of connection were raised, especially for people who might be isolated. Conversely, there was the view that face-to-face appointments with clinicians covered in PPE kit could be highly intimidating and arguably less personal than speaking to someone virtually.

Lack of privacy: a potential issue for those living with others and wanting to have a private conversation with their clinician. This was especially problematic for those with safeguarding issues, or those who wanted to discuss their mental health.

Fraud: albeit a minority view, there was a question over how clinicians would be able to check someone's identity remotely.

Loss of connectivity: what would happen if a patient had a bad connection or dropped out of the call.

Hacking: albeit a minority view, there was a concern about the security of platforms being used.

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There were also some practical concerns and questions raised around the use of video, online and telephone consultations

Out of all the measures discussed, this is the one where participants were most prone to spontaneously discuss groups that might be disadvantaged by the policy: Two groups in particular were recurrently mentioned among participants: the elderly and those with language needs. As the discussion progressed, additional groups were identified and concerns raised.

People experiencing digital access barriers:

- **The less digitally literate**: in addition to ensuring this group can carry on accessing face-to-face appointments, participants discussed how they (and especially the elderly) could be supported to go online.
- **The digitally excluded**: including those without a phone such as the homeless or the financially vulnerable.

People experiencing communication issues who might struggle to explain their symptoms in a video, online or telephone consultation:

- Those with **English as a second la**nguage: the use of interpreters was discussed but this was viewed as potentially difficult to arrange for patients.
- Those with **physical impairments** which might impact on their ability to communicate remotely (e.g. those with hearing and visual impairments).
- Those with **declining cognitive abilities or learning disabilities**.

Participants demonstrated altruism in nearly unanimously asserting their willingness for clinicians to continue to offer face-to-face appointments to people who might be disadvantaged by the virtual first policy. They felt GPs had a key role in identifying their vulnerable patients and discussed the importance of the NHS continuing to offer them choice, including the ability to opt out of video, online and telephone consultations altogether.

They also believed it was key to measure the impact of the policy on the most vulnerable, especially digitally excluded groups, as it had the potential to exacerbate health inequalities.

> “*If a certain percentage of us do have technology and are quite happy to see people virtually and we don’t have any serious issues, then definitely that is going to reduce the backlog in GPs and hospitals (…). Certain people it would not work for, but as long as they’re given the option of visiting their GPs, they should be allowed to do it (…). It’s important to get the list down and people to get their expert care as quickly as possible and get the bulk of people online so vulnerable people can be treated separately.”*
>
> **(Female from Ealing).**

Perspectives from under-represented groups and vulnerable communities

Participants with lived experiences felt strongly that those in vulnerable circumstances should be able to request being seen face-to-face if they wanted or needed to: echoing workshop discussions, these participants had concerns around how the virtual first policy could impact on disadvantaged groups who might experience digital exclusion, limited digital literacy and communication issues.

Participants worried that the measure could create additional access barriers for vulnerable people, and this could lead to missed diagnoses:

One Traveller participant explained how older people in her community would refuse to talk about health matters over the phone because they thought this was highly private and required a face-to-face conversation.

> *“That would be so embarrassing for them, it would be something that just slid under and they wouldn’t even mention it. It would be something that they would just ignore… [Talking about an older relative] Everything is private with them; you need them to go and see a doctor… If it was anything personal there’s no way they’d be letting someone else make that phone call.”*
>
> **(Female, Traveller).**

While it is important to note that some participants were not necessarily against carrying out telephone, video or digital consultations themselves, as for the general public workshops **there was a general consensus that virtual approaches would not work for everybody, and for every condition**.

> *“People who don’t have money to buy a computer, don’t have money for broadband, people who have had problems with alcohol and drugs, elderly people, they’ll need some kind of social contact, especially if that’s the only contact those people have…*
>
> *Vulnerable people, people at high risk, safeguarding, where you can’t tell if they’ve been abused or not, you need to asses them.”*
>
> **(Female, bipolar).**

However, views were split over the use telephone, video or digital consultations for mental health patients – some thought they could encourage people to seek help, while others thought they were not fully suitable.

Summary: participants created a statement of their expectations for policy makers (4)

4. It is reasonable to expect that, where possible, initial contact with patients should be virtual given the need to protect staff and other patients from potential exposure to Covid-19. However, this approach is not suitable for everyone and therefore the NHS should:

- Establish the needs and preferences of particular groups (the digitally excluded, people with language barriers, the elderly) and provide an alternative means to access health services when needed.
- Ensure that for certain consultations (e.g. those that require physical examinations, discussions around a patient's mental health, safeguarding cases), the default should be to offer a face-to-face appointment. Certain symptom criteria need to be set out to guide this.

Additional considerations in relation to under-represented and vulnerable groups (4)

The workshop with advocacy groups emphasised the following points:

- Virtual first is one of the policy areas that advocacy groups raised the most concerns about. They felt it didn't fully take into account the realities of digital exclusion, and were very concerned people will inevitably fall through the cracks.
- There is an increasing body of evidence around digital exclusion which needs to feed into the implementation of the virtual first approach.
- It is critical for communications around the policy to highlight potential alternatives to virtual consultations so that people are not deterred from seeking help.
- It is important to note that digital inclusion does not necessarily go hand in hand with the ability to communicate confidently virtually: a number of digitally included patients might feel uncomfortable explaining their symptoms in a virtual consultation.
- Linked to this, as people start re-establishing their lives post lockdown, it is possible that virtual consultations become less acceptable. This needs to be monitored.

Access to urgent and emergency care

The difference between urgent and emergency care was not clear-cut for participants

Examples given of why people might need accident and emergency care included car accidents, heart attacks, strokes, severe abdominal pain, major cuts and broken bones.

However, broadly speaking they struggled to distinguish between urgent and emergency care, assuming emergency care is predominantly for life-threatening situations, whereas urgent care would be those which can wait.

As participants discussed the area further, they recognised the difficulty of establishing whether a situation or condition was an emergency. Examples of these ‘grey areas’ included symptoms relating to existing conditions, chest pains (which could be anxiety induced, or something as serious as a heart attack), and children presenting with potential meningitis.

For some, the difference between urgent and emergency care was entirely unclear, not helped by a general lack of awareness of Urgent Treatment Centres (UTCs).

Personal reasons for accessing A&E were mixed. While some said that they would only ever use the service if their condition was extremely serious, others perceived A&E to be there for those unable to get, or wait for, an appointment with a GP.

There was a widespread perception that, as well as those who use A&E because they believe they need to be there, there are people who ‘abuse’ the system, using A&E as a way of accessing care regardless of their condition or circumstances.

[Reflecting on why you might access A&E]

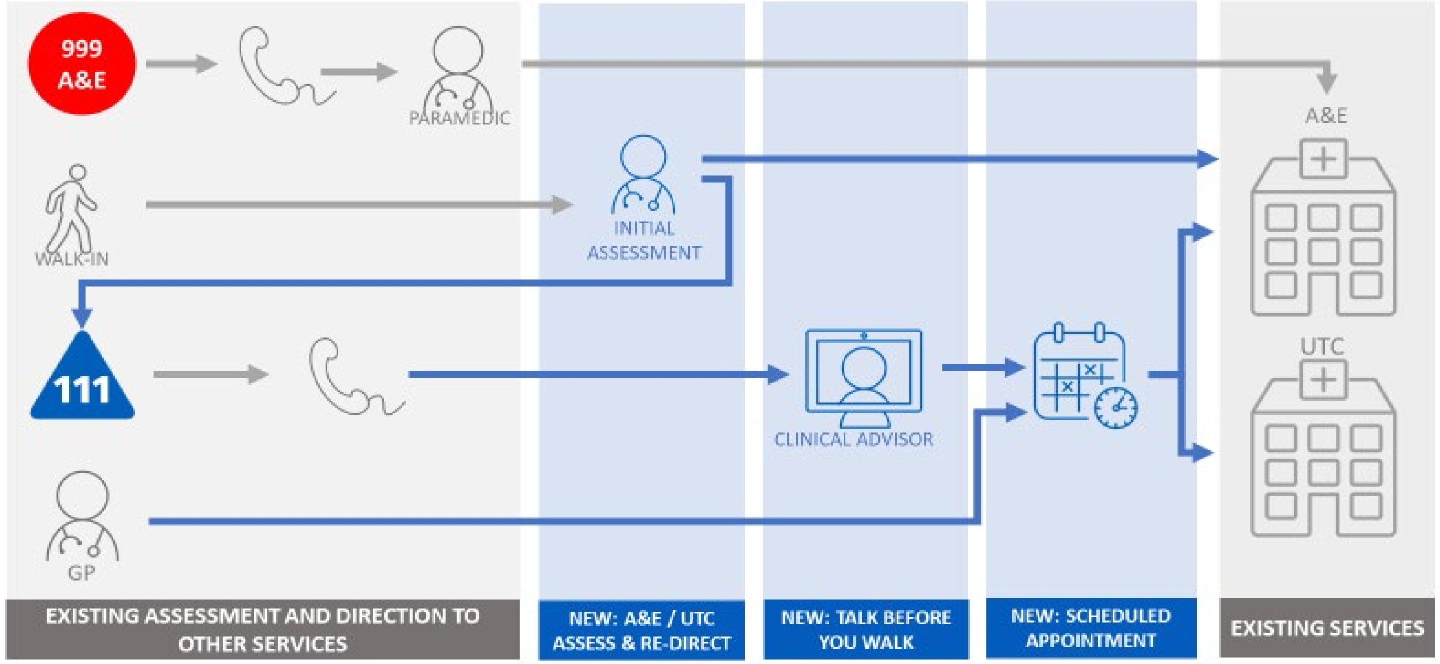
> “*There is some sort of imminent risk or consequence to not having the treatment done within a certain timeframe.*
>
> *If I was to go to A&E I would expect it to be something serious, I’ve broken a bone, my breathing is bad or something like that.”*
>
> **(Male from Southwark).**

Participants were presented with proposals around changing access to urgent and emergency care to reduce the risk of Covid-19 infection

Participants were informed that it is important to minimise the risk of infection while people wait for or receive care, helping people keep themselves and others safe, whilst also ensuring that people receive the most appropriate care for their need.

As such, participants were invited to discuss potential changes to how urgent and emergency care might be accessed during the pandemic (potential at the time – now policy).

The proposal involved encouraging people to use 111 more to receive advice about the best place for their care, and reducing the volume of people who might access A&E by redirecting them to services more appropriate for their need.



Through a range of stimulus materials and exercises, participants were asked to reflect on the following questions:

- How do you feel about the proposals?
- Who might these proposals work well for and who might they work less well for?
- What would make these potential changes more or less acceptable?

In principle, participants were accepting of the need for change in how patients access A&E

In the context of the pandemic, participants were almost universally supportive of the principle of reducing the volume of people in A&E waiting rooms to reduce risk of infection:

The proposed change in access was seen as a solution to a range of problems, not all of which are directly related to Covid-19. Participants recognised that A&E services are stretched and under pressure and that there are not enough doctors to meet the demand.

Some felt that addressing these challenges was long overdue. Several positives were consistently discussed:

Easing of the pressures on A&E and the staff that work within these.

A more efficient and productive management of the service.

Reduction in the spread of the Covid-19 virus, by controlling the amount of people in waiting rooms.

Better addressing people who are not aware that there are other services available.

> “*So whilst Covid-19 is a tragic situation, it’s actually created a positive situation here. It’s forcing the NHS and the government to force this idea through which has been long overdue anyway.”* **(Male from Enfield).**

> “*When we see people abuse it, and it’s our taxpayers’ money, we’re like, ‘No, let’s be quite strict with people.’ People need to take care of their own health. Hopefully it starts making people start to take care of themselves.”* **(Female from Barking and Dagenham).**

> “*In the situation we are in at the moment, you don’t want a lot of people sitting in the waiting room. If they can be seen by other services that aren’t as busy, and relieve the pressure on that.”* **(Female from Bexley).**

But they expressed anxiety and a lack of faith in the capability and capacity within the existing 111 service

Participants spoke of their concerns if 111 is essentially the ‘filter’ to urgent and emergency care:

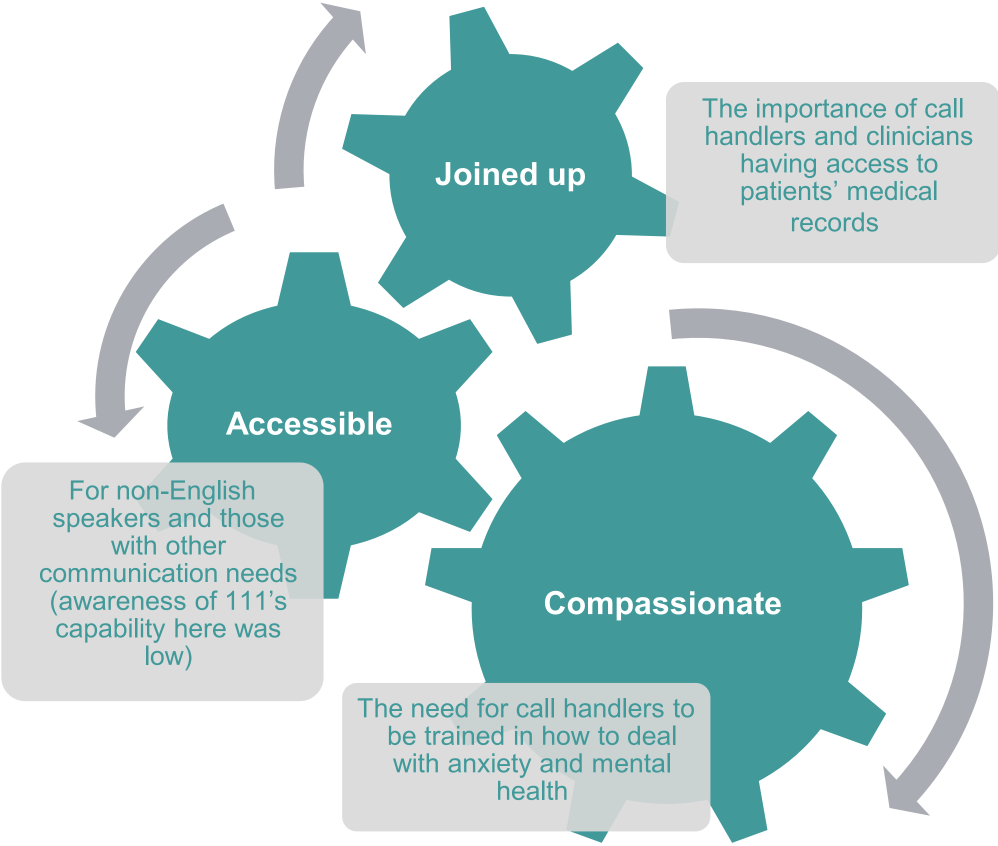
Participants raised several concerns:

- The ability and capacity of 111 to cope with the increase in demand.
- The training of call handlers.
- The ability of clinicians to pick up on mental health problems over the phone.
- It is difficult for vulnerable people, and those with communication problems, to explain their symptoms and medical history over the phone.

Participants also raised a number of concerns about heightened anxiety, as people will be waiting at home for their call back/ appointment, instead of in A&E, which in itself can be a reassuring place to be.

> *If people have support then that’s okay as most people are more comfortable in their own home anyway. But if you’re on your own and anxious you might have a panic attack.”*
>
> **(Male from Richmond).**

While some reported positive experiences of 111, others had had bad experiences, so lacked confidence in the system.



The importance of call handlers and clinicians having access to patients’ medical records

For non-English speakers and those with other communication needs (awareness of 111’s capability here was low)

The need for call handlers to be trained in how to deal with anxiety and mental health

It was clear that the proposal to contact 111 prior to A&E will rely heavily on behaviour change and communications

First and foremost, the public need to be aware of any change in access:

Participants immediately jumped to the need for a wide-reaching communications campaign.

They spoke of the importance of educating people that A&E is not the right place to be in the majority of situations.

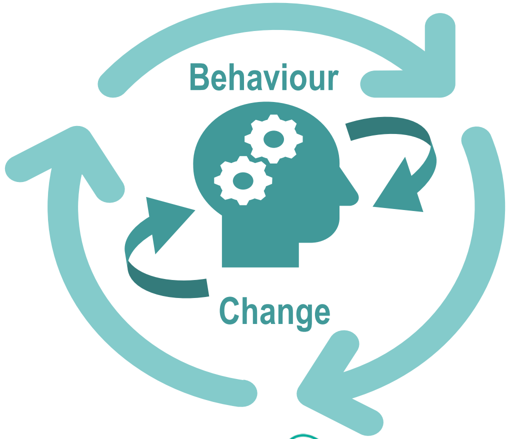
It requires behaviour change:

Although some were confident that people will eventually get used to the change in access, there will be a period of time where people will continue to walk-in to A&E. In addition, in the long-term there will be some people who use NHS services infrequently and will not be aware of the proposal to contact 111 prior to going to A&E, meaning there might be people who walk-in to A&E on an ongoing basis.

The NHS needs to create and instil confidence and trust in the system:

Participants spoke of the need for equivalent trust that the public has in the existing (walk-in) access to A&E.

> “*There are a degree of reassurances that need to be made for those that require critical or urgent care. The reassurance that they won’t slip through the net. Or if they are being diagnosed virtually, it is impossible to reassure no misdiagnoses, but people need to be reassured that they can trust this model.*”
>
> **(Female from Harrow).**



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There were practical suggestions concerning the use of 111 for triage

Support provided to people to access 111: Participants were clear that there would need to be support provided to people to access 111. There was widespread concern for those who might struggle to access 111 if asked to. For example, people without access to a phone, the elderly or people with communication challenges. They were clear that people would need to be supported to do so.

Expectations of 111 around the clinical call back:

- People should receive a call back within 2 hours, but ideally within an hour or even quicker (e.g. if it is a suspected heart attack) (participants were largely not aware that 111 already provides for this).
- In the meantime, call handlers should provide reassurance, pain management advice and signposting of where to go for more information.
- People should be kept informed about the progress of the call back. Some suggested that it would be more reassuring to stay on hold, and be told where you are in the queue. Others suggested the use of apps for updates.
- People should not have to repeat their story twice.

Expectations around appointments in A&E and UTCs: Participants were understanding that more urgent situations may delay appointments. Here, it was important to be kept informed (via text for example), to avoid arriving and being told that the service was running behind.

> “*I don’t think everyone has that common knowledge, especially if someone hasn’t had it before.*
>
> *Some sort of advice on what to do in the meantime.”*
>
> **(Male from Tower Hamlets).**

Londoners raised considerations when testing the idea of patients being redirected if they walk into A&E without accessing 111 or their GP first

Some patients are likely to continue walking into A&E rather than call 111 first. Participants discussed the approach that should be taken with these patients. Under the current policy, patients walking into A&E will continue to be treated at A&E. The discussion about what should happen to those walking in without accessing another service first was therefore hypothetical and designed to test a new idea rather than a more developed proposal.

Participants raised a number of considerations around what should happen in a hypothetical scenario in which those walking into A&E without accessing 111 first are not automatically treated in A&E and may be redirected to a more appropriate service.

The likelihood of conflict and challenges for staff:

Participants warned about the increased likelihood of A&Es being unpleasant working environments if staff redirected patients not needing immediate care to 111, since staff would inevitably have to deal with angry, frustrated and intoxicated people.

Suggestions were made by some for security back-up if this was going to be done.

The proficiency and role of those carrying out the initial assessment when people do attempt to walk into A&E:

If patients were to be redirected from A&E if they attend without accessing 111 or their GP first, participants expected that assessors making this decision would be clinically qualified, with the option to call for assistance if they were unsure about the condition of a patient.

Participants worried about the assessor’s ability to establish what was wrong, or where the patient needed to be, in the absence of a thorough physical examination or tests. They also thought that the area where initial assessments took place would need to be private, for example in a cubicle.

Some thought that assessors should be able to provide pain relief or bandage up open wounds, before they redirected people to 111, and this was important to them.

This new pathway would rely heavily on coordination with other services to ensure that there is enough capacity elsewhere to manage demand.

Some worried that the service would effectively be pushing the problems elsewhere.

The need for flexibility and exceptions would also be an important consideration if patients were to be redirected from A&E

Across the groups, participants cautioned the risk of people ‘falling through the cracks’ if patients were to be redirected from A&E.

> “I thought about non-English speaking people and if they’d just turn up anyway and get frustrated about being turned away. I wonder what will be put in place to deal with those issues.”
>
> **(Male from Richmond).**

As such, they would expect to see a certain amount of flexibility with regards to admitting people into A&E if they present there.

Decisions would not only need to be based on the clinical presentation of patients, but also on patient circumstances.

Those who might need to be given access to A&E included patients unable to get an appointment elsewhere, homeless people, gypsies and travellers, the elderly and the vulnerable.

Patients with mental health issues were generally assumed to be exempt given the risk of harm to themselves or others.

> “I’ve had friends and family members that have had mental health things ongoing and have stopped medication, and it’s a very serious situation because you don’t know how that person is going to be able to cope with an episode.
>
> So, it’s really important that when they turn up they get the targeted help they need and a quite urgent referral. It’s an urgent situation and they should certainly not be turned away.”
>
> **(Female from Hackney).**

A major risk that was flagged is that people who do really need to be in A&E may be deterred from seeking help.

> “The other issue is some people (…) if they get told to go away, it might be more difficult for them to reassess that for themselves and when they need to go back again.
>
> It's a big thing, although many people are now easing the idea of social distancing, the anxiety has obviously gone down but for people who have anxiety anyway they might build up that courage and then be sent away, they might not want to go back.”
>
> **(Male from Richmond).**

Perspectives from under-represented groups and vulnerable communities

This was one of the proposed measures that raised the most concerns among certain groups, especially homeless people.

> *A reason for homeless A&E use is down to alcohol, stroke, addiction (...) lack of personal care or some sort of consequence of a fight or whatever, so for a homeless person to need A&E (...) they wouldn't have the capacity to call 111."*
>
> **(Male, with lived experience of being homeless and substance abuse).**

Some participants could see some of the benefits of the proposed change, with accessing 111 prior to going to A&E (such as not having to spend longer periods of time in a stressful A&E waiting room, which could heighten the anxiety of patients experiencing a mental health crisis).
But overall, it was felt that the measure was not suitable for those experiencing communications barriers and digital exclusion.

> *50% of the homeless population doesn't have English as a first language. The others are people with issues – alcohol, drugs and mental health (…). They need those services, they need to go there, they need to talk to someone (…). A lot of time people don't have a phone."*
>
> **(Male, homeless and living in a hostel).**

Similarly to what was discussed during the workshops, some participants worried about 111 call handlers' ability to deal with complex patients. In addition, one participant explained how historically certain groups such as homeless people have had bad experiences with the service. There were perceptions that call handlers would not be able to help patients with no English or no address.

> *If English is not your first language, a lot of people will push you away (...) and if you don't have an address, they don't want to know."*
>
> **(Male, homeless and living in a hostel).**

Summary: participants created a statement of their expectations for policy makers (5)

5. In an effort to reduce the risk of spread of Covid-19, the NHS should restrict access to A&E and urgent treatment centres for only those who most need these services, as long as the following conditions are met:

- There must be clear and consistent messaging, widely communicated, around how to access urgent and emergency services and what to expect, to avoid the risk of confusion or deterring people from seeking help when they need it.
- The decision about who is seen in A&E / UTCs is made by a clinician (e.g. doctor, nurse, care assistant, paramedic) based on a conversation with the patient – this applies whether the patient presents at A&E or calls 111.
- If a patient presents at A&E / a UTC and it is deemed they could be more appropriately treated elsewhere, they must be directed somewhere their needs can be appropriately and quickly met (e.g. within 24 hours, or sooner if deemed as necessary) – 111 is not considered suitable as the only alternative option. There should be clear communications which state why the patient has been redirected, and what they can expect (in a way that people can understand).
- Any booked appointment should be followed by a reminder text.
- Advice, guidance and information around where to go for pain relief (e.g. pharmacy), how to manage their condition, and / or what to do if their condition deteriorates should always be provided to patients to support them whilst they wait for alternative care.
- The NHS must consider how it proactively supports everyone to access the care they need in a timely manner in light of these proposed changes, especially those groups who may be more disadvantaged by these changes.
- No one should be refused treatment.

Additional considerations in relation to under-represented and vulnerable groups (5)

The workshop with advocacy groups emphasised the following points:

- Any changes to the way people access urgent and emergency care, including having to call 111 first, might deter some vulnerable individuals from seeking treatment. Those who can’t call 111 (whether it is because they do not have a phone, enough credit, or might struggle to explain their symptoms over the phone) should not be discouraged from going to A&E or a UTC to seek treatment.
- As such, communications around the measure need to be carefully considered – the messaging needs to focus on what patients can do, rather than on what they cannot do.
- People need to be directed to the right place at the first point of contact.
- Smooth handover of care is key to instilling trust in the new system.

Summary: participants created a statement of their expectations for policy makers (6)

6. If 111 is to be used as the primary triage service for A&E / UTCs, the following conditions must be met:

- Ensure there is adequate capacity (people should not have to wait longer than 10 minutes) and clinical capability to meet the increase in demand and to support clinical assessment.
- Training for the initial call handler, particularly around mental health and care and compassion.
- People are kept informed of where they are in the queue / there is a call-back option (for people who can’t afford to hang on).
- Clear advice and guidance must be provided to those who are given appointment slots for A&E or a UTC, so that anxiety is managed as they wait at home/somewhere else.
- Patients should not have to repeat their story multiple times. Information should be available to healthcare professionals at all points along the journey from initial call to treatment (for example a reference number).
- Patients should not have to wait longer than 2 hours (or 1 hour if they are deemed as high risk, e.g. elderly, children) for a clinical call back following the initial assessment by the 111 call handler.
- 111 should be accessible to all (e.g. people speaking different languages, people with hearing impairments).

Additional considerations in relation to under-represented and vulnerable groups (6)

The workshop with advocacy groups emphasised the following points:

- The pandemic has amplified some of the communication issues already experienced by some groups.
- People from vulnerable groups may feel they have been stigmatised in the past, and so call handlers and assessors need to be adequately trained so people do not feel mistreated.
- Some of the training should focus on compassionate care.
- Poor experiences of the 111 service might deter people from seeking help again – it is critical that the initial contact with the service is good.
- There need to be some feedback mechanisms in place so that call handlers and staff can continuously learn and improve their communication skills.

Overarching themes

People have a responsibility to access and use NHS services sensibly. In turn, the NHS needs to be open and transparent about the proposed changes

In addition to reflections and concerns specific to each of the initiatives discussed, two overarching themes emerged from the workshop discussions: the role of individual responsibility, and concerns around vulnerable patients and individuals.

Participants were keen to highlight the importance of individual responsibility

There was general agreement that people have a key role in ensuring they access and use NHS services sensibly, especially in the context of the pandemic but also beyond it.

Linked to this, participants emphasised how they were willing to make compromises, including reduction of convenience and choice.

> “*I would like to see the public coming together. We've all got to make these changes. In a time like this, I think everyone appreciates the NHS a lot more.*
>
> *We need it now more than ever. It's not just the NHS that has to make changes. It's the public as well.”*
>
> **(Female from Wandsworth).**

Those views were often expressed as participants discussed how they were in favour of measures that had the potential to save the NHS money.

In the context of specific measures, individual responsibility for participants meant:

- Having honest conversations with NHS staff about whether they had self-isolated or not.
- Following comprehensive social distancing and hand hygiene before planned care.
- Accessing services such as A&E appropriately, through 111.

However, participants also stressed how they wanted the NHS to play its part in communicating the proposed changes to the general public transparently, consistently and in a timely manner. They believed this could be done through communication campaigns (both wide reaching or targeted at specific communities), but also through open and honest conversations between patients and NHS staff.

Summary: participants created a statement of their expectations for policy makers (7)

7. It is reasonable to expect that patients should take practical steps to access services responsibly as they too have a role in controlling the risk of spread of Covid-19. For example:

- Having open and honest conversations with their healthcare professionals about whether or not they have self-isolated, or who they have been in contact with, before a procedure.
- Maintaining social distancing and good hand hygiene before coming into contact with health services. People should be informed about the importance of these measures and the risks if they don't adhere to them.
- Accessing services appropriately and in the way that they are intended to be used, for example A&E for life threatening and emergency care only.

Additional considerations in relation to under-represented and vulnerable groups (7)

The workshop with advocacy groups emphasised that when highlighting personal responsibility, communications should not focus on what people shouldn't do, or cannot do. Instead, it needs to highlight what they can do and how to access services.

Participants worried about the impact of the proposed changes on specific groups, and wanted specific measures put in place for them

Concerns around how all of the proposed changes could negatively impact on certain individuals or communities – including those with complex medical needs or people in vulnerable situations – recurrently came up throughout the deliberations: echoing some of the dialogue discussions, participants were prone to spontaneously talk about how some of the changes could have a disproportionately negative impact on two specific groups: elderly people and patients with mental health conditions.

However, with further probing and the use of case studies, they started reflecting on how the changes could also impact on a number of under-represented groups and vulnerable communities.

> *My concern is the vulnerable people in society…There has to be consideration of the vulnerable, there needs to be a duty of care.*
>
> *The choice is being removed here and I'm not sure the care will be there for them."* **(Male from Bromley).**

As such, concerns around health inequalities and how the NHS should address them became a running theme throughout the deliberation:

- Participants were keen to see the NHS putting in place some specific measures for vulnerable patients and communities.
- They were also more willing to accept some of the proposed measures if this meant freeing up time and resources for more vulnerable patients.
- They were keen that the impact of the proposed measures on specific groups was monitored to ensure they did not exacerbate health inequalities.

> They need to put measures in place to support individuals who will be mostly affected by these issues. There are going to be barriers to access. It's fine to take it away, but they need to replace it with something, otherwise people will just turn up and ignore them." **(Female from Barking & Dagenham).**

> *Yes, you have to measure and monitor. Different needs for different people."* **(Female from Lambeth).**

Summary: participants created a statement of their expectations for policy makers (8)

8. It is reasonable to expect that in making future decisions about the delivery of healthcare services, decision makers must pay consideration to the impact and implications on specific groups. This would include:

- Putting specific measures in place for those who may be adversely impacted by the decision / policy, for example transport to be provided for those for whom travelling further for treatment is more difficult and / or unaffordable.
- Measuring and monitoring the impact of decisions / policies on specific groups, for example to better understand if virtual first is limiting access to health services for those who are digitally excluded.

Summary: participants created a statement of their expectations for policy makers (8)

The workshop with advocacy groups emphasised the following points:

- Safety netting and monitoring the impact of the proposed measures on vulnerable communities are critical.
- Equality impact assessments need to be carried out for each of the proposed changes.
- NHS staff need to be compassionate towards people as they navigate through these changes. Training needs to be provided.
- Linked to this, NHS staff need to understand that people may have experienced discrimination in the past and this could impact on the way they access, use and interact with different NHS services.

Communications

Londoners need to understand *why* policies are put in place, also guarding against the risk of overloading people with too much information

Participants were asked to reflect on which key messages Londoners and the general public need to be made aware of on each of the different policies discussed throughout the workshops. They were also asked to consider more broadly how those changes need to be communicated.

Overall, there was an agreement that **the rationale behind each policy needs to be communicated to the general public**. Participants emphasised the importance of public understanding of why a certain policy has been put in place to ensure or increase acceptability and trust.

Group discussions highlighted the need to achieve the **tricky balance between providing enough information to people without confusing or burdening them**.

To do so, some participants suggested spreading information over time rather than all in one go through a range of methods (billboards, TV adverts, social media, storylines in dramas, etc).

Strikingly, there was **no clear consensus** on the level of communications needed and who the messenger(s) should be:

- For instance, some participants wanted key figures and statistics about their local hospital whilst others worried about information overload, highlighting how they found it difficult to know which information source to trust.
- Some participants thought the greater the number of messengers, the stronger the message. But others thought too many messengers and messages could lead to confusion and be counter-productive.
- Some participants favoured local messengers (such as local authorities), while others considered national ones more effective.

There were however two points participants seemed to agree on:

- The government is not best placed to deliver these messages – the **NHS was perceived as more trustworthy**.
- **GPs and GP surgeries have an instrumental role** to play in communicating some of those changes.

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"The NHS is open for business" should be the underlying message throughout every communications campaign

Universally, participants were keen to stress that communication around these policies needed to focus on reassurance.

They were in agreement that the key message needed to stress that the NHS was open for business, and highlight what measures had been put in place to ensure safety when accessing NHS services.

> *Highlighting that the NHS is a safe environment generally. I know a lot of patients are scared of catching Covid-19 so they need to promote that it's still a safe environment. (…) patients need reassurance."*
> **(Male from Newham).**

- Linked to this, participants were keen to see the risks of delaying treatment and of cancelling or postponing appointments highlighted.
- Some participants discussed how local hospitals could also play an active role in delivering such messages.

> *They can say what they're doing to keep people safe. Just saying it's safe isn't good enough. How do they know it's safe? What is making it safe? I think they need to go through the measures that people would find. It will still be a lot of people that are sceptical of that message. I would be. What would safe mean? Can I sue you if I get it? I think we need to say what you're doing to keep people safe, as opposed to just saying it."*
> **(Male from Southwark).**

Communications around the proposed changes

Need to be transparent

Need to be reassuring

Spells out what is being done to keep services safe

Need to highlight individual responsibility

Remain brief and to the point

Explain why changes are happening

There was a consensus that any changes to urgent and emergency care access would need a wide-reaching communications strategy

Taking each policy in turn, participants reflected on what should be the key messages and how those should be communicated.

There was wide consensus that communications around changes to the way people access urgent and emergency care, including calling 111 first, required the most thought and resources as participants anticipated this measure would not only be the most contentious one amongst the public, but also the one which could negatively impact on people the most if they were unaware of the change (for instance, if the idea of redirecting people from A&E were to become a proposal or policy).

> *The A&E message is the most important. I know prioritisation has changed as well, but telling people we'll run the A&E in a different way is crucial."* **(Male from Southwark).**

Linked to this, participants highlighted the need to educate people about the different avenues to accessing emergency or urgent care.

> *I had never heard of urgent care before. I think they would need to really educate someone what urgent care is and the difference between the two, and what is considered urgent. I think they need to enlighten people about those differences and be clear about it."*
> **(Male from Southwark).**

While participants were mindful not to suggest big expensive communication campaigns (citing the NHS' limited financial resources), they recognised the need to devise effective and wide reaching campaigns – both local and national – to inform everyone about the change in access, and to initiate behaviour change.

> *It would have to be pretty broad because it's a massive shift and you're going to have to catch people at every point. TV, print advertising, maybe in free newspapers, maybe even through the apps that people use to book appointments at their GP."* **(Male from Haringey).**

However, there is more of a role for personalised communication from NHS staff for other policy measures

Virtual first

GP surgeries are best placed to relay information around this policy to their patients.

Participants also agreed that surgeries would have enough information about each patient to be able to identify those at risk of being disadvantaged by the policy.

There were also some conversations around the use of the term ‘virtual’ which participants found confusing and misleading.

> *The word ‘virtual’ itself is very broad because it’s not a word that people can identify with.”* **(Male from Wandsworth).**

Self-isolation

Communication around self-isolation needs to emphasise individual responsibility, the need for honesty and the communication of risks (to patients and NHS staff) associated with not following the precautions the NHS expects patients to take.

> *Not everyone is going to be honest but if they’re made aware of the possible risks and what we can do to prevent it from happening, that’s really important. I hope the majority of people would take that onboard and do the right thing.”* **(Female from Wandsworth).**

There is no need for a wide communications campaign. Information around what to do could be included in appointment letters and discussed with clinicians. One group suggested giving some guidance around what to do to minimise the risk of catching Covid-19 for those unable to self-isolate.

Prioritisation

It is important for people to understand the NHS has to make tough choices when it comes to prioritising patients for treatment.

It is important for clinicians to regularly keep in touch with people waiting for treatment so they do not feel forgotten.

> *I like the idea of communicating to those on the waiting list so they don’t feel forgotten. They can feel lost even if they haven’t been.”* **(Female from Sutton).**

Consolidation of elective care

Communications around consolidation of elective care need to highlight the rationale for it (i.e. infection control, reducing the backlog of appointments and making patients receive the best level of care) – reassuring patients is key.

It also needs to flag to people they can request transportation if needed (and eligible).

Key learning for the NHS when communicating changes

People want to understand the rationale behind each policy change
The NHS is trusted by the public and they think it is important to maintain this trust. To do so, the NHS shouldn't be afraid to have an open and honest conversation with people about the tough choices it faces, and why it needs to implement changes. This requires communications to educate people, rather than just to inform them about changes.

There needs to be different communication strategies for different policies
There is no one size fits all approach. While any changes to access to urgent and emergency care require a wide-reaching communications strategy, other policies might require a more personalised approach (e.g. a conversation between a patient and their clinician).

There needs to be different communication strategies for specific groups
It is important to have targeted communication strategies in place and use a mix of channels to reach certain vulnerable audiences.

Safety and reassurance should be at the core of every communication with the public
Some of the information delivered to the public needs to be framed positively. It needs to spell out what measures NHS services have been put in place to reduce the risk of exposure to Covid-19.

Communications should not focus on what people on what people shouldn't do, or cannot do
This point was raised by the advocacy groups who emphasised that the need for communications around the measures to highlight what people can do and how to access services.

Conclusions

Uncovering Londoners' expectations

The intended output of this dialogue and deliberation programme was an informed and considered set of Londoners' expectations to guide future planning and engagement at ICS level as further changes are made in the response to the pandemic.

Participants were directed to develop these expectations as guiding statements that are not binding, but rather will assist the NHS when making decisions about services during the pandemic.

This process complements local engagement activity and should not be confused with formal public consultation. The intention, therefore, was not to develop recommendations (e.g. 'The NHS must do X, Y and Z'), but rather for the participants involved to voice what matters most to them (e.g. 'We expect X, Y and Z to be borne in mind by decision makers).

How participants created statements of their expectations

- Expectations (or principles) are values or beliefs and as such it is not always easy for the public to verbalise these when prompted to do so. Instead, a common technique used in deliberation is to explore participants' views around a topic, and instead to listen out for their underlying expectations in doing so. Unlike recommendations, which tend to be written by participants and framed in their own words, the draft expectations were crafted by the Ipsos MORI and ICHP team based on the synthesis of discussions from previous workshops.
- During the final workshop, the draft expectations were presented to participants and it was explained how they had been developed (i.e. through a synthesis of the discussions) and therefore that they were the research team's reflection of what participants had told them.
- Each of the 10 groups were invited to review and discuss each of the expectations in turn. Participants were asked whether they thought (1) they reflected the discussions held in their respective groups, (2) whether there was anything that should be reformulated or reworded, and (3) whether there was anything missing.
- Feedback from the 10 groups was then reviewed and each expectation was refined as result of the feedback. The final expectations were then presented to the participants and a range of senior healthcare leaders from across London at the end of the final workshop.

Londoner expectations

1. Decisions around who should be prioritised for elective procedures should be driven primarily by clinical severity of the patient. Further consideration should then be taken into account to guide decisions around prioritisation of treatment with regards to:

- Level of pain/suffering (especially for those who have been waiting longer than 52 weeks). This should be regularly assessed by the patient's clinician.
- Impact on the person's quality of life, mental health and the wider impact of delays on their ability to work.
- Caring responsibilities and overall wellbeing.
- There should be regular dialogue with people waiting longer to ensure their condition has not deteriorated.
- Patients who have been waiting over a year should be offered first refusal on cancellation slots.

Londoner expectations

2. It is reasonable to expect that some patients may decide to delay their procedure because they are anxious about contracting Covid-19. In this situation the NHS should support the patient in the following ways:

- Every effort should be taken to inform them about the risks and implications of their choice.
- They should be given time (two to four weeks) to consider their decision whilst remaining under clinical review and be reminded as the period is coming to a close (e.g. automated text or letter).
- If they decide to go ahead with their treatment, they should return to the waiting list in a similar position to where they left it, but not at the expense of another patient's appointment, i.e. they might return to the front of the waiting list and be in line for the next available slot.
- If they decide after the allotted time period not to undergo treatment, they should be removed from the waiting list and return to the care of their GP.

Londoner expectations

3. It is reasonable to reduce choice of where people receive planned care in an effort to control the risk of spread of Covid-19, as long as the following conditions are in place:

- For those for whom travelling is extremely difficult and / or unaffordable, the NHS should ensure transport is provided. This should be assessed against criteria (e.g. means tested) and should be easy to book for those who meet the criteria.
- For those who may be anxious about attending a new facility for treatment, so much so that this is a barrier to treatment, the NHS should provide support to reduce this anxiety, e.g. volunteer scheme to provide a point of contact prior to the appointment to answer questions and provide additional information.
- Patients should still be able to opt to receive planned care in a place of their choice (i.e. instead of in an elective care centre), on the assumption that this might mean that they have to wait longer and that the NHS cannot guarantee a reduced risk from Covid-19.
- Patients who have very regular care needs, such as kidney dialysis or chemotherapy, should receive this closer to home to reduce the disruption of travelling further for them.

Londoner expectations

4. It is reasonable to expect that, where possible, initial contact with patients should be virtual given the need to protect staff and other patients from potential exposure to Covid-19. However, this approach is not suitable for everyone and therefore the NHS should:

- Establish the needs and preferences of particular groups (the digitally excluded, people with language barriers, the elderly) and provide an alternative means to access health services when needed.
- Ensure that for certain consultations (e.g. those that require physical examinations, discussions around a patient’s mental health, safeguarding cases), the default should be to offer a face-to-face appointment. Certain symptom criteria need to be set out to guide this.

Londoner expectations

5. In an effort to reduce the risk of spread of Covid-19, the NHS should restrict access to A&E and urgent treatment centres for only those who most need these services, as long as the following conditions are met:

- There must be clear and consistent messaging, widely communicated, around how to access urgent and emergency services and what to expect, to avoid the risk of confusion or deterring people from seeking help when they need it.
- The decision about who is seen in A&E / UTCs is made by a clinician (e.g. doctor, nurse, care assistant, paramedic) based on a conversation with the patient – this applies whether the patient presents at A&E or calls 111.
- If a patient presents at A&E / a UTC and it is deemed they could be more appropriately treated elsewhere, they must be directed somewhere their needs can be appropriately and quickly met (e.g. within 24 hours, or sooner if deemed as necessary) – 111 is not considered suitable as the only alternative option. There should be clear communications which state why the patient has been redirected, and what they can expect (in a way that people can understand).
- Any booked appointment should be followed by a reminder text.
- Advice, guidance and information around where to go for pain relief (e.g. pharmacy), how to manage their condition, and / or what to do if their condition deteriorates should always be provided to patients to support them whilst they wait for alternative care.
- The NHS must consider how it proactively supports everyone to access the care they need in a timely manner in light of these proposed changes, especially those groups who may be more disadvantaged by these changes.
- No one should be refused treatment.

Londoner expectations

6. If 111 is to be used as the primary triage service for A&E / UTCs, the following conditions must be met:

- Ensure there is adequate capacity (people should not have to wait longer than 10 mins) and clinical capability to meet the increase in demand and to support clinical assessment.
- Training for the initial call handler, particularly around mental health and care and compassion.
- People are kept informed of where they are in the queue / there is a call-back option (for people who can’t afford to hang on).
- Clear advice and guidance must be provided to those who are given appointment slots for A&E or a UTC, so that anxiety is managed as they wait at home/somewhere else.
- Patients should not have to repeat their story multiple times. Information should be available to healthcare professionals at all points along the journey from initial call to treatment (for example a reference number).
- Patients should not have to wait longer than 2 hours (or 1 hour if they are deemed as high risk, e.g. elderly, children) for a clinical call back following the initial assessment by the 111 call handler.
- 111 should be accessible to all (e.g. people speaking different languages, people with hearing impairments).

Londoner expectations

7. It is reasonable to expect that patients should take practical steps to access services responsibly as they too have a role in controlling the risk of spread of Covid-19. For example:

- Having open and honest conversations with their healthcare professionals about whether or not they have self-isolated, or who they have been in contact with, before a procedure.
- Maintaining social distancing and good hand hygiene before coming into contact with health services. People should be informed about the importance of these measures and the risks if they don’t adhere to them.
- Accessing services appropriately and in the way that they are intended to be used, for example A&E for life threatening and emergency care only.

Londoner expectations

8. It is reasonable to expect that in making future decisions about the delivery of healthcare services, decision makers must pay consideration to the impact and implications on specific groups. This would include:

- Putting specific measures in place for those who may be adversely impacted by the decision / policy, for example transport to be provided for those for whom travelling further for treatment is more difficult and / or unaffordable.
- Measuring and monitoring the impact of decisions / policies on specific groups, for example to better understand if virtual first is limiting access to health services for those who are digitally excluded.

Appendices

Annex 1: Participants' characteristics

The cohort for the dialogue and deliberation process has been recruited from a group designed to reflect the diversity of London, including ethnicity, age and socio-economic status - as demonstrated below.

There are 59 participants spread across the five London Sustainability and Transformation Partnerships (STPs) - 11 from South East London STP and South West London Health and Care Partnership; 12 from East London Health and Care Partnership and North London STP, and 13 from North West London STP.

Gender

Female	34
Male	25

Age

18-39	18
40-59	25
60+	16

Socio-economic category

B	25
C1	12
C2	6
D	7
E	9

Ethnicity

Bangladeshi	1
Black African	2
Black British	5
Black Caribbean	10
Indian	4
Mauritian	1

Non-British European	2
Other mixed background	1
Pakistani	1
White and Black Caribbean	2
White British	30

Caring responsibility

With	35
Without	24

Health and social care usage

Light	21
Medium	22
Heavy	16

Annex 2: list of the advisory group members

The Advisory Group provides oversight, direction and challenge to the Dialogue Phase and Deliberation Phase to ensure their credibility and utility. It is constituted until the publication of outputs from the Deliberation Phase, but its constitution may be extended by agreement of both the Advisory Group and NHSE/I London Region.

The group is comprised of members with a range of experts and key stakeholders from across the region. The Advisory Group membership is as follows:

- **Mike Cooke** (Chair), Chair of NCL ICS
- **Charlotte Augst**, CEO, National Voices
- **Simon Burall**, Senior Associate, Involve
- **Dr Silvia Camporesi**, Ethicist, Kings College London
- **Olivia Clymer**, Healthwatch (Central West London)
- **Dr Tom Coffey**, Health Advisor to the Mayor of London
- **Emer Delaney**, Head of Communications, NHSE/I London Region
- **Dr Vin Diwakar**, Medical Director, NHSE/I London Region
- **Dominic Dodd**, Chair, The Royal Free London NHS Foundation Trust
- **Prof. Kevin Fenton**, Regional Director for Public Health, Public Health England
- **Helen Keynes**, Lead for patient and public engagement, NHSE/I London Region
- **Prof. Peter Littlejohns**, Emeritus Professor of Public Health, Centre for Implementation Science, King's College London
- **Martin Machray**, Joint Regional Chief Nurse and Covid-19 Incident Director, NHSE/I London Region
- **Dr Andrew Murray**, SW London CCG Chair and Co-Chair of the SW London Clinical Senate
- **Frances O'Callaghan**, Accountable Officer, NCL ICS
- **Martin Pratt**, Deputy Chief Executive and Executive Director Supporting People, London Borough of Camden
- **Marie Price**, Director of Corporate Affairs, NELCA
- **Prof. Julian Redhead**, Medical Director, NWL ICS
- **Andrew Travers**, Chief Executive, Lambeth Council

Annex 3: list of the experts and observers that attended the workshops

Experts that attended the workshops came from a variety of different medical backgrounds, some with lived experiences of decision making and facing dilemmas in light of the pandemic.

The list of experts that attended at least one of the workshops, are as follows:

- **Amy Darlington**, Director, ICHP
- **Prof. Andrew Rhodes**, Consultant in Anaesthesia and Intensive Care Medicine, St George's
- **Andrew Travers**, CEO, Lambeth Council
- **Axel Heitmueller**, Managing Director, ICHP
- **Carena Rogers**, CWL Healthwatch
- **Carolyn Regan**, CEO, West London NHS Trust
- **Ceri Jacob**, representing the NHS in North East London
- **Christina Windle**, representing the NHS in South East London
- **Dr Chris Streather**, Chief Medical Director, Royal Free Group
- **Dr Cathy Cale**, Medical Director, Hillingdon Hospitals
- **Dr Helene Brown**, GP and Medical Director, NHSE (London)
- **Dr Jo Sauvage**, GP and CCG Chair, NCL CCG
- **Dr Katherine Henderson**, President, RCEM
- **Prof. Kevin Fenton**, Regional Director for Public Health, Public Health England
- **Dr Ruth Brown**, Consultant in emergency medicine, Imperial College Healthcare.
- **Dr Vin Diwakar**, Medical Director, NHSE/I London Region
- **Emer Delaney**, Head of Communications, NHSE/I London Region
- **Frances O'Callaghan**, Accountable Officer, NCL ICS
- **Jane Clegg**, Chief Nurse, NHSE/I
- **Dr Jonty Heaversedge**, GP and CCG Chair, SEL CCG
- **Joy Beishon**, Patient/Public Voice, Greenwich
- **Katie Harrison**, Comms Lead, ICHP
- **Laura Cockram**, Head of Policy and Campaigns, Parkinson's UK
- **Lesley Watts**, representing the NHS in North West London
- **Lisa Moore**, Comms Lead for Urgent and Emergency Care, NHSE/I London
- **Mark Kewley**, Director, ICHP
- **Mike Cooke**, Chair of NCL ICS
- **Olivia Clymer,** Healthwatch (Central West London)
- **Prof. Paul Plant**, Deputy Regional Director for Public Health
- **Rachel Matthews**, Programme Manager, National Voices
- **Rosemary Watts**, Assistant Director of Engagement, SEL CCG
- **Sarah Stayt**, Comms Lead, Hounslow CCG
- **Sir David Sloman**, NHS Regional Director for London
- **Steven Platts**, Chief Executive, Groundswell
- **Tom Brown**, Director of Community Services, Lewisham Council

Annex 4: List of participating advocacy groups

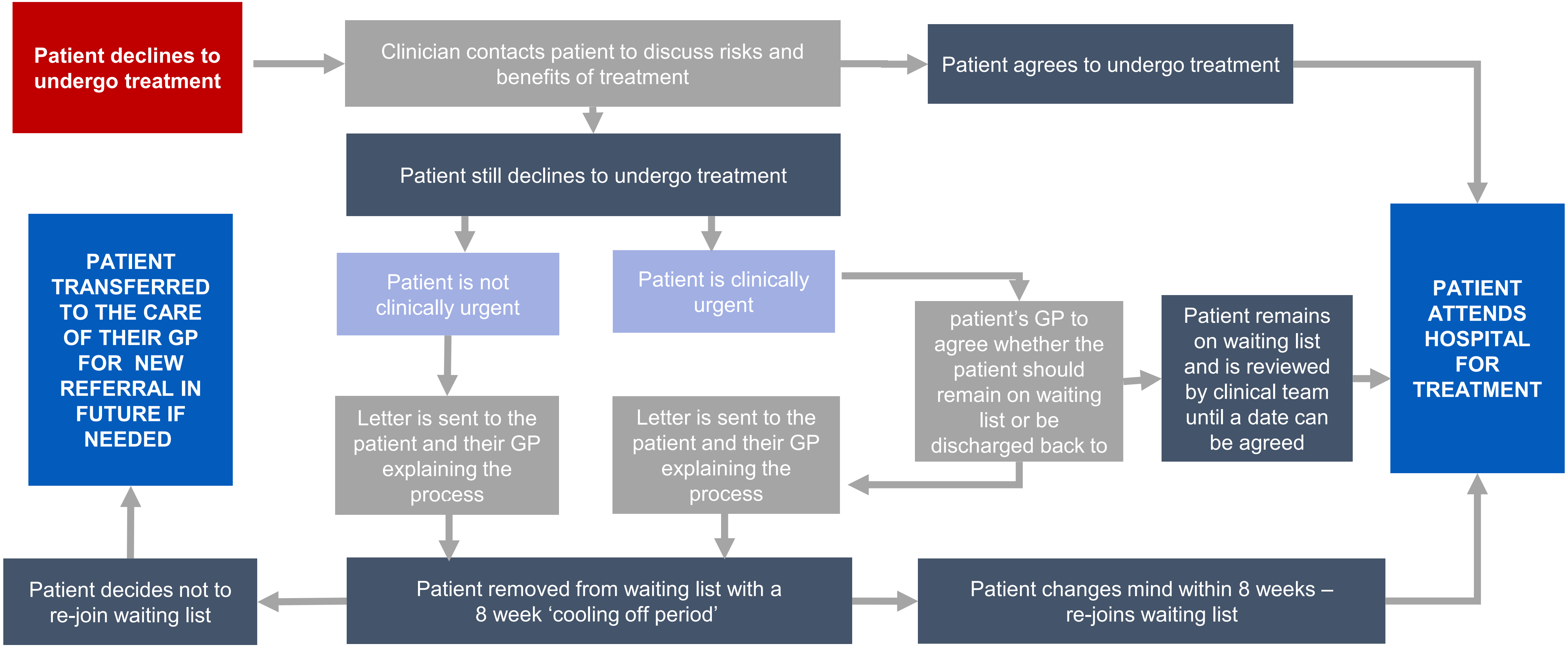
List of advocacy groups interviewed

1. Groundswell
2. Doctors of the World
3. Patient engagement group from a mental health trust
4. Centre for Ageing Better
5. Peer Power
6. Diabetes UK
7. London Gypsies and Travellers
8. London Maternity Voices Partnerships
9. Advocacy Greenwich

List of advocacy groups that took part in the sense-check workshop

1. Patient engagement group from a mental health trust
2. Centre for Ageing Better
3. London Gypsies and Travellers
4. Advocacy Greenwich
5. National Voices

Annex 5: Participants' handout describing NHS South East London approach to patients deferring treatment



Patient declines to undergo treatment

Clinician contacts patient to discuss risks and benefits of treatment

Patient agrees to undergo treatment

Patient still declines to undergo treatment

Patient is not clinically urgent

Patient is clinically urgent

patient's GP to agree whether the patient should remain on waiting list or be discharged back to

Patient remains on waiting list and is reviewed by clinical team until a date can be agreed

PATIENT ATTENDS HOSPITAL FOR TREATMENT

PATIENT TRANSFERRED TO THE CARE OF THEIR GP FOR NEW REFERRAL IN FUTURE IF NEEDED

Letter is sent to the patient and their GP explaining the process

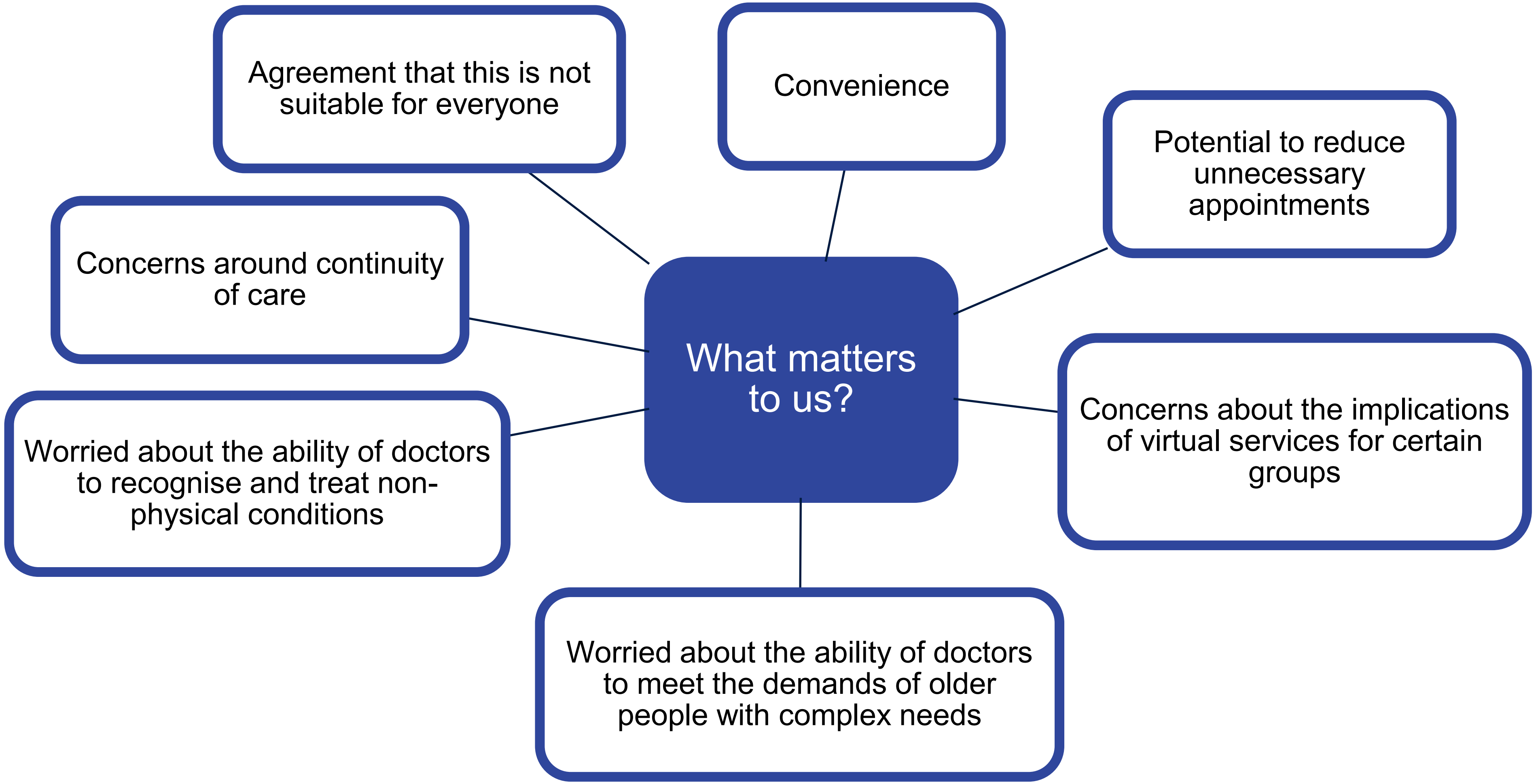
Letter is sent to the patient and their GP explaining the process

Patient decides not to re-join waiting list

Patient removed from waiting list with a 8 week 'cooling off period'

Patient changes mind within 8 weeks – re-joins waiting list

Annex 6: Participant handout – Your views on reducing unnecessary physical contact by implementing a ‘virtual first’ policy



What matters to us?

Agreement that this is not suitable for everyone

Convenience

Potential to reduce unnecessary appointments

Concerns around continuity of care

Concerns about the implications of virtual services for certain groups

Worried about the ability of doctors to recognise and treat non-physical conditions

Worried about the ability of doctors to meet the demands of older people with complex needs

London Covid-19 Dialogue & Deliberation

Commissioned by NHS England (London)
Delivered by Imperial College Health Partners and Ipsos MORI

INTERIM REPORT – early insights from a Dialogue with Londoners

June 2020

Contents

Overview:

Background and methodology

How to read this report

1. **This interim report draws together findings from an initial dialogue with Londoners**, which took place across two virtual workshops. This first phase of the dialogue and deliberation programme was intentionally used to bring Londoners up to speed on some of the ways that the NHS has responded to the Covid-19 pandemic, and may respond in the future, and seek initial reactions to these. During the subsequent deliberative phase, the same participants will be supported to explore in more detail the real life dilemmas that decision makers are faced with and the associated trade-offs in order to develop a set of principles to inform future decision making.
2. **Linked to the point above, the insight presented in this interim report reflects a high level discussion** around a set of broad measures. Further, given this stage was about gathering initial reflections, we intentionally did not push participants to weigh up the benefits and risks, nor did we set parameters about what might and might not be feasible. It was important to gather initial insight to expose initial reactions, concerns and tensions.
3. **Finally, this report focusses almost entirely on NHS services.** This is not to say that significant changes have not occurred across the care sector too, however, the topics being discussed during the dialogue phase related solely to NHS services where the policy dilemmas are much clearer.

Background

In response to the Covid-19 public health emergency, rapid change was implemented across all levels of the London health and care system. Measures were implemented at pace and therefore engaging with the public on these was extremely challenging. It is important that we understand how Londoners feel about the changes that have already been put in place as part of the emergency response. Further, as we plan our response to the next phase of the pandemic in the Capital there is an opportunity to explore Londoners' expectations in relation to mid to longer-term measures and in particular the dilemmas and trade-offs these may create.

Working with Londoners, through a process of dialogue and deliberation, NHS England (London region) commissioned Imperial College Health Partners (ICHP) and Ipsos MORI to deliver a two-stage dialogue and deliberation project. The aim is to explore these dilemmas in partnership with Londoners to understand their expectations and inform future decision making, specifically exploring the tensions and trade offs. This will culminate in an informed and considered set of principles to guide future planning and further engagement at ICS level. This process complements local engagement activity and should not be confused with formal public consultation.

Stage 1: Dialogue

Aim: To explore Londoners' hopes, fears, concerns and expectations in relation to the measures being put in place in response to the pandemic to gather insights to inform stage 2.

Stage 2: Deliberation

Aim: Using insights gathered from the dialogue phase, explore Londoners' expectations of the mid-to longer term measures that could be put in place in response to the pandemic and the potential implications of these.

An innovative approach to developing policy in partnership with the general public

Deliberation is a progressive form of public engagement that can successfully help to shape public policy due to its ability to provide informed and considered public opinion.

It convenes 'mini publics' reflective of a broader population over an extended period of time. Participants are informed by experts and supporting stimulus about the topic/s in question and then invited to explore and deliberate trade-offs associated with this.

This method creates an opportunity for decision-makers to understand public views that are carefully considered and rooted in real-life context, thus leading to more trusted and supported policy in the longer term.

Approach for the dialogue stage

Overall approach

- Two virtual workshops were conducted on Wednesday 3 June and Saturday 6 June, each lasting three hours.
- The workshops comprised a combination of plenary sessions in which information was provided to participants, smaller break-out groups of around six people where participants discussed the issues in detail, and plenary sessions in which moderators summarised the discussions in the group for all participants to hear.
- In the first workshop, 58 participants attended, with 61 participants in the second workshop.
- Experts attended the workshops and were available to answer participants' questions.
- Alongside the main workshops, and as part of the dialogue phase, we conducted interviews with advocates of vulnerable groups. To both explore the impact of the measures that have, or might be put in place on these groups but also to feed into the design of the next phase.

Participants

- The participants for the dialogue were drawn from 100 Londoners who took part in the OneLondon Citizens' Summit – a previous deliberation about uses of health and care data across London. As well as being reflective of Londoners, this group were also recruited to represent a range of views towards data and digital technology.
- Drawing people from the OneLondon project meant that participants were already familiar with the deliberative process and with each other therefore making the transition to a virtual workshop much smoother. However, this also meant that the participants were more informed about the NHS than the 'average' general public.
- Participants were recruited with quotas to ensure 12 from each STP/ICS area and a spread of demographics. The profile of the participants can be found in the appendices.

Structure of the workshops

Workshop 1

This comprised a combination of group discussions to understand experiences during the pandemic and initial responses to some of the changes the NHS had made and difficult decisions being faced. Stimulus included a presentation describing the NHS' immediate response to the pandemic, a roundtable of experts explaining difficult decisions they were facing and a presentation on access to health services during the pandemic.

Workshop 2

This comprised group discussions reflecting on the first workshop, initial responses to the measures being considered within the NHS and then a more detailed exploration of four areas (consolidation of services, virtual by default, triaging access to A&E, prioritising planned care). Stimulus included a presentation explaining these four areas at a high level and case studies demonstrating how they might impact on individuals both positively and negatively.

Gathering enhanced insights from under-represented groups and vulnerable communities

Why does this matter?

In order to really understand the views of Londoners, we need to engage with a wide range of people. The cohort for the dialogue and deliberation process has been recruited from a group designed to reflect the diversity of London, including ethnicity, age and socio-economic status.

However, we know there are some people who may be under-represented in the cohort due to access issues (digital or societal). We therefore want to enhance our understanding of their views through targeted engagement.

Who have we talked to so far?

We have spoken to a range of advocacy groups who helped to provide insight from across specific populations who may have been disproportionately impacted by 1) the virus itself; and / or 2) measures put in place to address it.

Those include groups representing people with specific medical needs and / or vulnerable communities (a full list of organisations is included in Appendix 3).

How will insights gathered inform the deliberative phase of the project?

Our interviews with advocacy groups also aimed to inform the design of the following phase of deliberative engagement with under-represented groups and vulnerable communities to ensure their voices are included in a meaningful way.

Overall, there was a widespread consensus that direct engagement with those with lived experiences is key so that the deliberation process and final principles are informed and challenged by the priorities and perspectives of specific populations. However, this might not be possible for all groups and the views of outreach staff and volunteers could also be valuable to bring those insights to participants.

02.

The NHS response to the pandemic in London:

Initial reactions, concerns and questions

Initial views, assumptions, concerns and questions

Before being introduced to the measures put in place by the NHS to respond to the pandemic, participants were invited to share their initial thoughts about the Covid-19 pandemic, and the NHS' response to it.

General views on the response to the pandemic

Participants thought that the NHS has done a 'sterling job' in managing and responding to the pandemic. There was an enormous sense of pride towards the NHS and its staff.

"The NHS staff have been doing their jobs, doing what's necessary. They're amazing." **(Male, workshop 1)**

This was in contrast to the criticism expressed by participants towards the government. In these discussions, it was clear that participants were not entirely aware of how decision-making operates within and between the NHS and the government.

Overarching assumptions

- Some of the measures taken by the NHS to cope with the crisis will last for a while.
- While the NHS has been underfunded in the past, the government is now willing to find the necessary resources to ensure it can cope with the pandemic.

Although some participants felt the worst of the crisis was behind them, a majority discussed the possibility of a second of wave of Covid-19 cases and the NHS needs to prepare for it, in response to the expert presentations. As a result, it was assumed that that the NHS will have to make long-term changes to the way care is planned and delivered.

Concerns

Participants felt anxious about accessing NHS services being fearful of:

- Being exposed to the virus (especially in hospitals and A&E waiting rooms).

  "I've just avoided going to the doctor. Unless I'm bleeding to death. I'm worried, I don't want to come into contact with people." **(Female, workshop 1)**

- Overburdening an overstretched NHS

Participants were initially prone to discuss concerns relating to their own health and wellbeing. However, as the dialogue progressed, they spontaneously started reflecting on how difficulties and anxiety around accessing and using NHS services could have a disproportionately negative impact on certain **vulnerable groups** (such as the elderly and people with mental health conditions).

Questions

Participants asked a range of general questions around the virus itself (such as 'when is the vaccine going to be ready? Or 'Why are BAME groups more affected than others?').

They also raised some questions around the practicalities of the NHS' response to the pandemic and how decision-making operates (and especially the roles of the government and the NHS in taking tough decisions) such as:

- How financially sustainable are the measures put in place by the NHS as a response to Covid-19?
- Can private hospitals help to take on some of these waiting list for non-urgent surgery?

Views on how the NHS has responded to the Covid-19 emergency

Overall, participants were fairly supportive of the measures that have already been put in place by the NHS as a result of the Covid-19 pandemic. This apparent support was underpinned by some views and assumptions discussed on the previous slide – mainly participants' strong sense of trust towards the NHS and their concerns over the potential occurrence of a second wave of infections as they learnt that this was likely. However, they also expressed a range of concerns around how long those measures would be in place for, and how they might potentially impact some vulnerable groups and communities.

Participants were presented with some of the changes to the way NHS care has been delivered during the pandemic, including:

- Staffing changes (staff working across sites, staff redeployed to support Covid-19 patients)
- Service delivery changes (coordinating services and closing or pausing services)
- Changes to how patients are seen (appointments by phone/video, families not being able to accompany patients to appointments or visit patients in hospitals)

Awareness of the measures put in place by the NHS was mixed

Participants had heard of the concept of remote and virtual care. They had also heard of planned care being paused (through personal experiences or in the news).

However, they were mostly unaware of the service delivery changes around the concentration and coordination of services, and more particularly the creation of non-Covid sites.

"I wasn't aware that non-Covid patients were moved to specific hospitals like Barts for heart attacks or for cancer treatments or another hospital for non-COVID related illnesses (…) I don't know if the general public were. If they weren't, it would mean they were scared to go to hospital."
(Female, workshop 1)

Participants felt that more effective communication of those measures was crucial going forward

They felt it was important that the general public fully understand the changes occurring within the NHS services and that more effective communication was key to this.

They agreed this could help alleviating people's fears and concerns about using NHS services, and in doing so incite them to access services when they have a medical need. This was especially important to participants as they shared concerns around people with conditions worsening and left undiagnosed if they did not access services in time.

However, participants agreed that the communication of those changes needed to come from the NHS rather than the government.

"At the beginning, I would have said the government should have led on this, but since they've been contradictory, they need to take a backseat and let the professionals deal with it."
(Female, workshop 1)

There was a general agreement that the measures put in place were sensible in the context of the crisis

Overall, participants were accepting of the changes. As an immediate reaction, they were willing to compromise convenience if this meant safety from Covid-19 but also safety from other conditions for them and for others.

Yet, they expressed concerns about how some of those measures could impact on certain vulnerable groups and communities (see slides 11-14).

Finally, some participants were hopeful that the pandemic could lead to positive longer-term changes in the way people access and use NHS services – especially A&E.

"(People) go to A&E for a headache, they don't think of going to a chemist or taking a pill. So, maybe it will change how people go to hospitals."
(Male, workshop 1)

03.

Exploration of potential future interventions:

What matters to Londoners, and insights from advocates of vulnerable groups

Separating emergency and planned care onto different sites

Participants were introduced to the potential of consolidation of services, which where possible could allow for restarting routine treatment or care whilst minimising the risk of infection, though this may have implications for access.

For the majority of patients, this measure appeared sensible, with safety predominantly the priority here.

The measure was tolerable for the majority, with some referencing that people already travel for specialist care (Moorfields, the Royal Marsden), or to settings known for better outcomes. Given the difficulty of keeping patients separate within buildings, the importance of keeping people safe, but also the need to reduce the safety risk of routine care not going ahead, it was perceived as sensible despite the need for people to potentially travel further for their care.

But as discussion deepened, the downsides associated with continuity of care and the need to travel emerged.

However, some were concerned about the need to use public transport, due to the risk of infection and other challenges such as the cost. Almost universally participants were less accepting of the impact of this on vulnerable people (e.g. the elderly, those who are financially deprived).

> *"Going back to my parents, it's a good idea to separate care, but if the elderly have regular appointments and it's further away, there will be an issue about them getting there."* **(Female, Workshop 2)**

There was also concern about the requirement to self-isolate before treatment: the practicalities (e.g. people self-isolating but then being at risk on public transport en route to hospital), and how it will unfairly impact on those who need to keep working from a financial point of view and therefore cannot self-isolate.

Practical mitigations

- Patients should be offered the opportunity to speak with the (new) surgeon beforehand if they need to be treated by a different clinical team – to reduce likely anxiety.
- Patient transport should be prioritised for those who need it (those unable to afford taxis, those with pre-existing health conditions, the elderly or vulnerable).
- During stays in hospital, patients should be offered a means for keeping in touch with relatives (iPads for facetime).

And participants worried about the impact on patients (anxiety) of being seen by a different specialist to the one they had been referred to / someone who was not their usual consultant.

As discussion deepened, several assumptions arose.

Preparedness to travel further was linked to frequency. While it felt reasonable to travel across London for a one-off operation, it felt less so for more regular appointments or for post-operative care.

> *"The post-care, yes she goes and has the operation at this other hospital, but she can't be expected to keep going back there for the post-operation care. She could maybe be referred to her local surgery."* **(Male, Workshop 2)**

Some vulnerable people would need to be offered treatment closer to home. Because of the worry for people at higher risk of the disease, and uncertainty around the ability of the NHS to offer infection free and sustainable patient transport.

Some felt that individuals should be given choice around whether to take up the offer to receive treatment further from home, or to wait longer for treatment closer to home. This view was not universal, however, and some argued that the clinical need for quicker access to treatment should override individual choice around where the treatment takes place. They too were worried about the implications of people choosing to wait, on waiting lists.

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Implications for under-represented groups and vulnerable communities

The consolidation of emergency and planned care was seen as problematic for most of the advocacy groups interviewed, as it was felt this could create additional barriers to accessing and using NHS services for:

- Those who are financially vulnerable and who might not be able to afford the travel costs associated with travelling further for their care (e.g. parking or public transport costs).
- Those with no access to private transport and having to rely on public transport to get to their appointment – which could put them at greater risk of infection from Covid-19.
- Those with mobility issues (e.g. people with a physical disability, frailty issues and women in labour).

Some concerns were also raised about how:

- Certain groups historically struggle to attend appointments (e.g. young patients, those with multiple complex social challenges such as homeless people) and how increased travel time would be likely to exacerbate this.
- How the measure could impact on continuity of care – which is especially important for some groups such as people with learning disabilities, and vulnerable young people.

Finally, there was also an acknowledgment that the requirement to self-isolate before a planned intervention might not be practically possible for those living in over-crowded accommodations.

Prioritising planned care to appropriately meet increasing increasing demands

Prioritising patients waiting for treatment, with some people having to wait longer because they are deemed as less urgent, was introduced in the context of the increase in the number of Londoners waiting for non-emergency planned treatment due to these services being paused during the early stages of the pandemic. It was explained that there is a need to address this backlog, but that the NHS cannot treat everyone at once.

Decisions around who should be prioritised for treatment first were driven by the severity of the condition (life threatening, risk of deterioration)

Participants were fairly accommodating of the need to make tough choices around who is offered treatment first, recognising the difficult task the NHS faces with already long waiting lists, and some presuming that the NHS has to do this in normal times.

While there were some inherent assumptions in how they weighed up options for addressing the backlog (see opposite), the severity of the condition was the main driver of how care should be prioritised. Those whose lives are threatened in the absence of treatment, as well as those with conditions that could deteriorate quickly (cancer), took precedence over those with less serious needs (tonsillectomies) even if this meant waiting longer.

> *"I'm on a waiting list. I've got skin cancer on my leg. It can wait, so I would rather someone more important took my turn."* **(Female, Workshop 2)**

However participants assumed this would be managed on a case-by-case basis

Participants were challenged when introduced to the case study (a delivery driver on sick leave in need of back surgery). Some concluded that decision makers need to consider the wider impact of further delays on people's financial situations, caring responsibilities and overall wellbeing.

In addition, as participants considered the impact on different groups of people, concern for vulnerable people became a factor. Those with mental health problems for example, and the general anxiety associated with further delays.

It was clear, as participants discussed prioritisation, that acceptability of this measure was underpinned by several assumptions.

- Decisions would need to be made on a case-by-case basis: Participants did not appreciate that the system will need to make decisions based on pathways, or cohorts of patients.
- The private sector could step in to alleviate some of the pressure on the NHS. They often referred to how patients could be treated in private hospitals, if capacity within the NHS was an issue.

The case study used to portray the implications of this measure mentioned the possibility of the patient (who was already on a waiting list) being given the option to have the operation sooner, but at a different hospital further away, and with a different consultant.

Participants thus tended to focus on the individual's choice here. In some cases, this took the focus away from a discussion about the principles of prioritisation, and instead became one about choice.

Reducing the volume of people in A&E by using telephone triage and creating an appointment system

Participants were introduced to NHS 111 telephone A&E triaging rather than a walk-in A&E service, meaning some people can avoid coming to A&E at all and others can be offered an appointment. This would reduce the number of people in the waiting room therefore reducing the risk of infection, although patients would spend some time waiting at home before their appointment.

The measures was welcomed for its potential to keep people safe while also offering a convenient service

Reactions to the suggested measure were generally initially positive. Participants were predominantly drawn to the idea of being protected from potential risk of Covid, though convenience and patient comfort were also appealing.

> *"A lot of the time you've hurt yourself and you're waiting in A&E, if someone could tell me when to come in, it would be so much better than waiting for hours and hours. I'm surprised they don't do that already."* **(Female, Workshop 2).**

As well, some were supportive of this measure for its potential to remove unnecessary A&E attendance.

> *"I like that they're streamlining people. My mother-in-law always tells me that people come to A&E with ridiculous demands. This sort of thing cuts waiting time and it's getting rid of the stuff that doesn't need to be in A&E."* **(Female, Workshop 2).**

Participants assumed that there would need to be a level of prioritisation and flex within the appointment allocation based on need and urgency.

Practical mitigations

- Life or death emergencies (road traffic accidents, heart attacks) should be exempt from the triaging system.
- The system would need to be well communicated (e.g. a televised announcement).
- Increased capacity in 111 would be required to alleviate call delays.
- Pain management advice should be provided by call handlers to reduce patient anxiety.
- There would need to be mechanisms for escalating if someone's condition worsens.

However, there were some concerns around the detail

The measure, however, raised several concerns and questions:

- Concern about people 'abusing' the system meaning those in real need of appointments may have to wait longer.
- Caution over the ability of some to describe symptoms over the phone (people with learning disabilities or language barriers, parents on behalf of their children). In addition, they questioned the call handler's ability to properly assess in the absence of a physical examination (the difference between a sprained or fractured arm for example). This linked to worries about non-medical NHS 111 call handlers following scripts and making decisions.
- Worry appointment slots would be quickly filled, and questions around the plans in place if this were to happen.

Accordingly, some discussions started to identify alternative means for reducing overcrowding in A&E waiting rooms (e.g. waiting outside, or using buzzers in the same way restaurants do).

The case study (a child with an arm injury) hit a nerve among some – notably those who were parents themselves. Though not universal, some were uncomfortable with the idea of waiting at home for a time, expressing they would value the comfort of being 'on site' physically, even if this did put themselves at risk of contracting Covid. It was unclear how serious the emergency would need to be here however.

Implications for under-represented groups and vulnerable communities

Reducing the volume of people in A&E by creating an appointment system was probably the most contentious of the proposed measures discussed with the participating advocacy groups representing vulnerable communities.

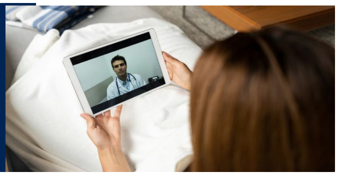
It is important to note that some groups are more likely to visit A&E services and urgent care centres than the general population for medical advice, especially those with no permanent housing facilities and or who are not registered with a GP (e.g. homeless people, Gypsy and Traveller households living roadside, asylum seekers and refugees). It was therefore felt that this measure might create challenges on their ability to access care if implemented widely.

Some concerns were raised about the practicalities of using NHS 111 to access urgent care, including how:

- Some groups might struggle to describe symptoms over the phone (e.g. people with language barriers or learning disabilities, people having mental health crises or those who are under the influence of alcohol or drugs).
- Some people might not have access to a phone, and some might use a pay-as-you-go phone and might not have enough credit to make a call.
- People with no or limited English would be able to understand the different automated menu options to request an interpreter.

It was believed that shifting health behaviours in relation to A&E use might be problematic for certain groups and urgent investment in outreach medical services for vulnerable populations would be needed to avoid the necessity of having to go to A&E to seek help.

Reducing unnecessary physical contact by implementing a ‘virtual first’ policy



Participants were informed that to minimise patients’ or staff travel as much as possible to reduce risk of infection, some care could be provided virtually while the patient is at home. This might mean implementing a ‘virtual first’ approach which would mean the vast majority of initial contact with the health service is virtual e.g. via a telephone.

Virtual consultations are welcomed, in a digital world and to provide convenience for many

This measure was not new to participants, some with direct experience of virtual GP consultations. There were comments that this had come at the right time, given that we now live in a digital world.

The measure was seen to work for people in straightforward circumstances and was liked for the convenience factor, and (like some views towards the A&E triaging), the potential to reduce unnecessary appointments.

However it was felt the system will not be suitable for everyone and for every situation.

With further consideration participants began to question aspects of the approach, concluding that it will not be suitable for everyone and for every situation.

- How would it work for people who do not have access to the internet, or are computer illiterate?
- How will doctors recognise and treat non-physical conditions such as mental health problems?
- How will GPs meet the demands of older people with multiple conditions and complex needs, requiring more attention?
- How will continuity of care be accommodated, as well as gender matching for those who require this?
- Could district nurses visit people in the community?
- Who decides who gets a face to face appointment?

In the absence of exceptions, participants cautioned that there could be misdiagnoses and undetected conditions.

Of all four of the Covid-related measures that were introduced to participants in the dialogue, this one became the one where Covid-safety was not necessarily the most important risk factor.

“Yes, but safety from other illnesses as well, minimising the risks in other areas as well. The focus can’t be entirely on safety from Coronavirus, you have to protect against it but if all efforts are focussed on that and other things go misdiagnosed, then it’s useless”. **(Female, Workshop2).**

This linked to a cautious message to healthcare leaders to weigh up the risk of Covid against the risk of other harm.

“I’m concerned as well, I would hate for it to become the case where they get so myopic on Covid that everything else falls by the wayside.” **(Male, Workshop 2).**

Practical mitigations

- Initial consultations could happen virtually but there must be flexibility for doctors and / or patients to decide to see people in person thereafter, if there is good reason to believe that this is necessary.
- An alternative approach is required for vulnerable people (e.g. those with learning disabilities or the frail).
- Doctors and patients should utilise home testing solutions (e.g. blood pressure monitors) to assist with the provision of care in the absence of physical contact.

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Implications for under-represented groups and vulnerable communities

Reducing unnecessary physical contact by implementing a ‘virtual first’ policy was received with mixed reactions. Although there was an acknowledgment that virtual and remote appointments could benefit certain groups or individuals (e.g. young people, some patients who might prefer to talk about their mental health conditions online), participating advocacy groups raised a number of concerns and questions in relation to:

- **Digital exclusion and digital literacy**: as discussed on slide 16, some people might not have access to a phone, or only to a PAYG phone. In addition, some groups (e.g. older people and the financially vulnerable) might not own a smart phone, or not be digitally literate enough for video consultations – it was felt this could exacerbate health inequalities with vulnerable individuals only able to attend appointments over the phone, which was seen as less effective than a video consultation.
- **Language barriers:** it was suggested that the ‘virtual-first’ approach was not appropriate for people with limited English, but also people with communication difficulties. Concerns were also discussed around how some people – who would usually rely on family members or carers to communicate with healthcare professionals on their behalf – would be able to attend virtual appointments if they lived on their own and had to isolate.
- **Continuity of care**: some questions were raised around how the measure could negatively affect continuity of care, and the overall relationships between healthcare professionals and vulnerable patients.
- **Safeguarding issues**: it was felt virtual consultations might prevent vulnerable adults or children from discussing a range of issues – because they might lack the privacy to do so but also the less interpersonal nature of such consultations.
- **Discussing mental health**: while some patients might prefer virtual consultations, there were concerns raised that some patients often feel that face-to-face consultations provide a more comfortable and open environment to discuss their mental health as they enable the patient to feel listened to and that their mental health needs are being taken seriously.

04.

Planning for the deliberation:

Implications for the next phase

Planning for the next phase – design of the public deliberation

The deliberation phase must further explore some of the genuine dilemmas faced by the NHS in relation to future Covid-related interventions. The details of these are evolving from week to week as the perception of risk changes.

- **Planned care:** Given the need to address the backlog, how should the NHS decide which caseloads of patients it prioritises? Is it ethical and fair for the NHS to require patients to self-isolate before a procedure given how this could detrimentally impact some groups more than others, and won't necessarily be observed by all anyway? What are the implications for those who can't self isolate, or for those who can? Should the primary focus still be on reducing the risks of Covid or does ensuring that people receive the care that they need factor in these decisions?
- **Unplanned care:** Given the need to reduce the footfall in A&E to reduce the risk of transmission of the disease, what would need to be true for a 'talk before you walk' care pathway to be an acceptable or better alternative to walk-in access to A&E? Where are the red lines and should a measure like this only be in place for some groups of people or all recognising the risk of potentially exacerbating existing health inequalities? Given that people are worried about the risk that care being delivered virtually will exacerbate inequalities, when is it appropriate to implement virtual first and where are the red lines?

Now that this group has been introduced to some of the key issues and it recognises the challenges at a high level, during the next phase we must:

- **Push harder on the trade-offs:** to further explore the implications of proposed interventions and understand how the public weigh up the potential risk and benefits of each. We need to understand what matters most to people and why, and importantly where the red lines are – what makes interventions more or less acceptable. We need to explore cases at the margin, to help inform how an operational policy would be developed.
- **Set parameters:** so that participants know what is and is not feasible. To avoid unrealistic expectations being set it is important that participants are clear on the practical constraints that the NHS operates within and that need to be considered e.g. workforce capacity.
- **Unearth a set of general principles:** which can be observed to guide specific decisions.

There is scope to use the next phase to also explore some of the practical features of implementing such measures with the public:

- **Consolidation of emergency and planned care:** How should patient transport be managed and who should be prioritised? How should the NHS respond if patients decline the offer to travel further and decide instead to wait for treatment closer to home?
- **A&E triaging and assessment:** How should the NHS decide how it offers and manages appointments? How should it utilise the existing 111 service?
- **Virtual first:** How will the NHS meet the needs of those for whom virtual consultations are unsuitable, while also trying to keep patients and staff safe?

Implications for engaging under-represented groups and vulnerable communities

Participants in the dialogue workshops were initially prone to discuss concerns relating to their own health and wellbeing. When probed on how accessing and using NHS services could have a disproportionately negative impact on certain vulnerable groups, they often showed an interest in discussing how the current pandemic and the lockdown had affected elderly people and patients with mental health conditions.

The case studies used during the second workshop helped participants to move beyond this and reflect on how the changes (current and proposed) to the delivery of NHS care could potentially negatively impact on some groups more than others. The deliberation phase plans to go further by exposing participants to the concerns and struggles of specific under-represented groups and vulnerable communities.

We believe it is crucial to include the voices of under-represented groups and vulnerable communities in this project through:

- **Actively engaging them** – by talking to people with lived experiences.
- **Exposing Londoners to their voices,** their fears, and their hopes and what the proposed measures might mean for them.

In doing so, we aim to ensure that the final principles are also informed and challenged by the priorities and perspectives of a range of vulnerable and under-represented communities.