

# Gathering Views Report on Waiting Times Guidance

August 2023



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## Section 1: Executive summary

- 1.1 The Scottish Government has undertaken a review of the current <u>NHS Waiting Times</u> <u>Guidance</u> which was last updated in 2012. The Guidance will help to make sure that patients are managed fairly and consistently across the whole of Scotland while providing healthcare that is person-centred, safe and effective. The aim is to provide clear, up-to-date and accurate guidance to support patients, their families and health boards. It should also be sustainable for the future delivery of services. The Guidance should be accessible for all, providing clear roles and responsibilities for both patients and health boards.
- 1.2 Healthcare Improvement Scotland Community Engagement & System Redesign was commissioned to undertake a Gathering Views<sup>1</sup> exercise in February 2023 to support the development of the Guidance. It is also intended that the recommendations from this exercise will be used to inform its future development.
- 1.3 The Gathering Views exercise was undertaken during March and April in 6 different territorial NHS board areas in Scotland, namely Lanarkshire, Borders, Shetland, Grampian, Tayside and Forth Valley. Individual interviews took place via telephone calls, video calls and in face-to-face settings. The work involved gathering people's views on the proposed changes and updates to current Guidance. This report sets out what we heard from participants around information, communication and support needs, as well as their views on particular policies and proposed changes, including concerns and issues around them.
- 1.4 A total of 38 people across Scotland took part in this exercise over a six week period. Interviews were organised through engagement offices using links through local contacts, NHS services and third sector organisations. A mix of participants from all demographics were sought and representation was achieved reflecting a mix of urban, rural and island community views.
- 1.5 Based on findings from this Gathering Views exercise, the report discusses views on the following key topics:
  - Information needs when on a waiting list
  - Thoughts on "Patient Focused Booking"
  - Thoughts on "implied acceptance"
  - Preferred ways to receive information
  - Thoughts around being referred to a team rather than a specific consultant

<sup>&</sup>lt;sup>1</sup> You can find out more out our approach to Gathering Views, and read our previous reports, at <u>www.hisengage.scot/gathering-views</u>.

- Support needed when offered an appointment outside the local area
- Thoughts on the "reasonable offer" of appointment
- Thoughts on "resetting the clock" for all patients
- Thoughts on "reasonable delay"
- What matters most about Waiting Times Guidance

A summary of the recommendations follows below, for the Scottish Government to take forward, working where appropriate with NHS Scotland, health boards and partner organisations. Further details around the recommendations and specific aspects that should be considered are provided in Section 5:

## **Recommendation 1**

## Consider the range of information needs highlighted by the participants throughout this piece of work:

- Ensure that patients receive all required information around process, practicalities, available support, and options. This needs to be provided enough in advance and should cover their journey from start to finish.
- Ensure this information is up-to-date, clear, appropriate and accessible, and that it is provided in a range of formats according to patients' needs. Consider initially focusing on aspects that participants highlighted are complex and not as easy to understand, for example around the "reasonable offer" of appointments.
- Ask patients about their preferred communication methods and ensure these are used.
- Provide a contact point to ensure patients know where to go to ask questions including if their condition deteriorates.
- Ensure communication is open and provides opportunities for a two-way dialogue.

## **Recommendation 2**

Consider the findings in this report in order to improve the processes and communication around Patient Focused Booking, implied acceptance, referral to team rather than individual consultant, attending appointments out of area, reasonable offer of appointment, resetting the clock, and reasonable delay:

- Ensure timescales for the processes discussed are appropriate and take into consideration the needs and circumstances of individuals and groups. When mitigations or exceptions are in place, these need to be communicated clearly to patients.
- Ensure information around these processes and the terminology used is clear, easy to understand and communicated to patients appropriately, according to their needs.

• Ensure the processes are explained to patients further if needed, to ensure understanding of the processes and how they may affect their waiting journey.

## **Recommendation 3**

Ensure the development and implementation of these processes, is person-centred and does not unfairly impact individuals and groups:

- Consider how these processes can be more "human" and person-centred, for example, by taking patient needs and circumstances into account, ensuring that measures are not perceived as punitive, and patients are aware of their responsibilities and options. This could be for example, providing alternative ways for people to reschedule appointments if they are not able or prefer not to do this via telephone.
- Continue working on Equality Impact Assessments (EQIAs) for each of the processes discussed, to identify impacts on different groups and people with different characteristics. Address these impacts through putting mitigations in place. Continue to review the Equality Impact Assessments (EQIAs) as needed.
- Health boards to review national EQIAs and complete local EQIAs to identify local impacts. Local EQIAs should be informed by local engagement with user groups around these processes, to ensure all patients are being supported.

## **Recommendation 4**

Consider further exploring, at a local level, the reasons why patients miss or don't book appointments, in order to identify barriers for individuals and groups and put mitigations in place.

## **Recommendation 5**

## Ensure the processes and changes discussed in this work consider the 2012 NHS Scotland Charter of Patient Rights and Responsibilities:

- Consider how the patient rights and responsibilities outlined in the Charter are reflected in the processes discussed, and any changes required to ensure increased alignment.
- Consider working on increasing patient awareness and understanding around the Charter, including how information in the Charter is communicated and how this may be done more effectively to match the information needs outlined in recommendation 1, such as alternative formats. This work could include engagement around the Charter to identify with the help of users how it can best be used by patients and communicated, and how to ensure patients understand how Waiting Times Guidance is aligned with the Charter.

## **Recommendation 6**

Moving towards implementation of the Waiting Times Guidance, the Scottish Government should liaise with NHS boards to ensure engagement is carried out with local communities to understand the changes that may directly affect them and their potential impact. This should be in conjunction with local Equality Impact Assessment (EQIAs).

## Section 2: Background

- 2.1 The purpose of Healthcare Improvement Scotland is to enable the people of Scotland to experience the best quality of health and social care. Healthcare Improvement Scotland Community Engagement & System Redesign is committed to supporting the engagement of people and communities in the development of health and social care services.
- 2.2 In February 2023, the Scottish Government commissioned us to undertake a Gathering Views exercise. This was to support the ongoing development of the <u>NHS</u> <u>Waiting Times Guidance</u> to ensure people have input into the development of the Guidance. The feedback will be used to develop Guidance that is clear, accurate and up-to-date for health boards, patients and their families.
- 2.3 In addition, and working alongside this Gathering Views exercise, the Scottish Government asked us for 2 additional pieces of work:

Firstly, the National Treatment Centre's (NTC) webpage on <u>NHS Inform</u> required an updated Frequently Asked Questions (FAQ) section to reflect the information that patients with an appointment at a NTC, may find of benefit. Healthcare Improvement Scotland sought volunteers to provide feedback on some questions that people may have when deciding to go to a National Treatment Centre so that a FAQ section could be developed. 11 volunteers participated in the exercise from across the North East of Scotland. Link to report.

Secondly, different volunteers were asked to work through a number of scenarios, using the NHS Inform online platform. A survey was created, which consisted of nine questions aimed at exploring the site and reporting on the ease of its access. It was shared amongst 18 different people across Scotland. Detailed steps on how they found the information was collected. They were also asked to share their views on what information patients visiting an NTC would find helpful. A short report to capture feedback was written. Link to report.

This information is provided here as further context to ongoing work in this area. These additional pieces of work are not discussed further in this report.

## Section 3: Approach

- 3.1 Healthcare Improvement Scotland Community Engagement & System Redesign has developed an approach called Gathering Views<sup>2</sup>. This aims to gather lived experience views on specific subject areas to inform the development of health and care policy and services.
- 3.2 Gathering Views exercises are not undertaken as formal research, nor as formal public consultation. The engagement is intended to supplement work undertaken by the Scottish Government or other commissioners, consider new or different ideas and make recommendations based on the findings.
- 3.3 The Scottish Government is completing an Equality Impact Assessment (EQIA) for each of the updates to Guidance being proposed with an overarching EQIA then being prepared for the Waiting Times Guidance Review as a whole. This will then be used by health boards to complete their own assessments at a local level.
- 3.4 The question set (<u>Appendix 1</u>) was developed to help us to gather people's views, insights and experiences with accessing and using the Guidance. Ten questions, some with supplementary questions, were asked.
- 3.5 An information sheet was provided for the participants as well as a consent form to take part in the work and all participants provided written or verbal consent in advance of the interview (Appendix 2).
- 3.6 Equality monitoring questions, in the form of an online survey, were shared with the participants, either before or during the discussion (<u>Appendix 3</u>), which they could complete via email or paper copy. This achieved a 58% response rate.
- 3.7 Recruitment methods were agreed based on the scope and aims of this work. We carried out 38 individual interviews over a six week period, collecting extensive and in-depth responses. Following a qualitative approach and according to the objectives of this work, the aim was to collect rich and meaningful feedback from a wide demographical range of people from across Scotland.
- 3.8 The questions covered the following areas:

<sup>&</sup>lt;sup>2</sup> There are several examples of our previous Gathering Views exercises available on our website <u>https://www.hisengage.scot/gathering-views</u> where this report is also published.

- Information needs when on a waiting list
- Thoughts on "Patient Focused Booking"
- Thoughts on "implied acceptance"
- Preferred ways to receive information
- Thoughts on being referred to a team rather than a specific consultant
- Support needed when offered an appointment outside the local area
- Thoughts on the "reasonable offer" of appointment
- Thoughts on "resetting the clock" for all patients
- Thoughts on "reasonable delay"
- What matters most about Waiting Times Guidance
- 3.9 The themes that emerged from the questions can be found in the <u>feedback and</u> <u>recommendations</u> section of this report, as well as recommendations which were identified during the analysis process. Where appropriate, we have used anonymised quotes from people who participated to illustrate what we heard. Quotes are not associated with any identifiable characteristics, such as location.
- 3.10 The analysis process followed a qualitative approach. All participant responses were themed and categorised, identifying a number of key and overarching themes which are discussed in this report. The recommendations were developed to address key points in these findings and are directly linked to the views and experiences shared with us during this work.
- 3.11 The interviews were challenging at times for both participants and interviewers because of the complexity of the processes that needed to be explained to participants. The information was shared beforehand, including visuals which were then talked through by Engagement Officers who were conducting the interviews.

## Section 4: Feedback

This section outlines the key points and themes from all the feedback collected through this Gathering Views exercise. Conclusions and recommendations based on these findings are outlined in section 5.

## 4.1 Information needs when on a waiting list

When participants were asked what would be helpful for patients to know once they had been accepted onto a waiting list for treatment, they highlighted three aspects:

- having information around process, practicalities, support and options
- getting clear, up-to-date, appropriate and accessible information, and
- having a contact point and being informed.

## Having information around process, practicalities, support and options

Participants highlighted that information needs to begin early in their journey and continue throughout. Information needs to cover the process from start to finish, and they would want to know what to expect while on the waiting list, as well as during and after their appointment.

They want to have a better understanding of the process, for example, how the booking system works, what number they might be in the queue, and what the consequences would be if they cancelled or missed an appointment or weren't able to attend due to holidays or extreme weather conditions.

Most participants felt that knowing the timescales associated with the waiting list was incredibly important, and that these should be shared alongside confirmation of the initial appointment. They also wanted to have an understanding of what types of support and resources are available. This could be, for example, information on transport and travel assistance, expense claims, and support for visitors and carers, but also what mental health support is available and what else they can do to support themselves while waiting, such as self-care, meditation, or other therapies. Another important aspect was to know what to do if health issues escalated while on the waiting list and before their appointment.

Participants also wanted to know what to expect from their appointment and what they should be doing in preparation for their visit. This could be, for example, whether they would need to follow a particular diet or exercise, and if they will need overnight clothes. Most participants highlighted the importance of providing details about the hospital they are attending, such as directions, maps or diagrams. They also wanted to know what to expect after the appointment and to receive some care planning advice. As one participant said:

"Within a leaflet or factsheet it would be helpful to receive information about what to expect on the day of your procedure, so you can go prepared, for example, to be told what time you are likely to be seen."

One participant thought it is also important to provide information on Patient Rights and NHS Commitments, which could help set expectations.

Options around treatment and appointments were also mentioned as being important to know about. One participant was keen to have information on potential options when offered an appointment in a different city. They were concerned about not knowing what might happen if they refused an appointment in a different location, saying:

## *"I'd be scared to refuse an appointment in case I am removed from the waiting list or put back to the beginning - I'd feel better knowing my options."*

In terms of options around treatment, others, for example, mentioned wanting to know whether "paying for treatment" and going through private healthcare was an option and whether this would speed up their waiting time.

Getting clear, up-to-date, appropriate and accessible information

Participants highlighted that providing the information described above is not enough, however; the information needs to be clear, concise, up-to-date, easy to understand, using simple language and easily accessible. It should be provided in different formats, for example audio, enlarged format and braille, Makaton, and in different languages. As one participant said:

## "You don't want a booklet 12 pages long, people won't read it or won't retain it."

Participants also felt that it would be important to ensure that the information is easily understood by patients, so for example where a patient requires an interpreter, they should receive confirmation of this being in place before the appointment. This would support those who don't have English as their first language and British Sign Language (BSL) speakers.

Some also suggested that, when needed, information should be condition-specific rather than generic. This would enable patients to have a better understanding of what they can expect from their appointment and treatment, which was very important to participants, as highlighted above.

Some were also keen to better understand the terminology associated with the waiting times system. For example, they thought that having a description or definition of frequently

used terms and phrases, like 'urgent' and 'non-urgent' and the distinction between 'Does Not Attend (DNA)' and 'Can Not Attend (CNA)', would be useful to support understanding.

## Having a contact point and being informed

Having the information mentioned above and in an accessible and understandable format was important to participants. They also highlighted, however, the need for a contact person. This would be someone that can answer their questions while they are on the waiting list, and they said that having someone to talk to about the process would be beneficial and reassuring. It would also be someone they could contact if their condition deteriorated during their wait and they would keep patients informed of any changes or updates to their appointment or waiting time. As one participant said:

"It would be helpful to receive an acknowledgement from the relevant department to say that you have been added to a waiting list, including who you could contact in between."

## 4.2 Thoughts on "Patient Focused Booking"

We asked participants what they thought about "Patient Focused Booking". This is the process where patients receive relevant information and are asked to arrange their own appointment. If no appointment is made, they receive a reminder 7 days after the original correspondence. If no appointment has been made after a further 7 days, their case is sent for review to the clinical team. Following this, the patient's 'waiting time clock' is reset to zero and the patient is removed from the waiting list and referred back to their GP, or they are offered another opportunity to make an appointment<sup>3</sup>.

Following a <u>brief explanation of this process</u>, participants shared their views about this approach and also offered some concerns. This was mainly around timescales, the process of 'resetting the clock', and issues around communication and process.

## Support for this approach

Nearly all participants agreed with the principle of Patient Focused Booking and understood why it is beneficial. For example, some participants said they agreed with it being the patient's responsibility to arrange their appointment. Some thought that people are familiar with this process and that the patient is more likely to attend their appointment if they are asked to arrange it themselves, as they explained:

<sup>&</sup>lt;sup>3</sup> A patient's waiting time is referred to as a "waiting time clock". "Resetting the clock" means that the patient's waiting time will be moved back to a zero ("reset") and the calculation of waiting time restarted. You can find more information on the waiting times clock and processes around waiting times on <u>NHS Inform</u>.

"I can see why this could be beneficial, particularly for the NHS as there are a lot of wasted appointments."

"When I read this it made sense, that's what we've had to do with the COVID vaccination appointments. It's not a foreign idea to a lot of people, I would say that people are used to the approach now."

## Concerns and issues around this approach

While most agreed in principle, however, they also discussed concerns and potential issues. A number of participants shared experiences of where similar processes had not worked as intended for them and they wanted to ensure this could be avoided in the future.

For example, a participant received an invitation to a telephone appointment but never received the phone call, and it was "put down that I had missed the appointment and (I was) taken off the list". That was a year ago and they are still waiting for a new appointment. Another participant received notification that their spouse was being removed from the waiting list with no prior communication, with no information around the reasoning (they had not missed any appointments) and no clinician involvement. A further participant received information by post about an appointment with a consultant while they were away on holiday, so they weren't aware of this. As a result, this was flagged to their GP as them not attending the appointment.

## **Timescale issues**

Most participants raised concerns about the proposed timescales. The vast majority said the 7-day timescale between the initial and reminder communications should be extended. There was no consensus on what that new timescale should be, with participants' suggestions ranging from 10 to 21 days. When explaining why this timescale should be extended, participants said:

- The person may be away from home, for example, visiting family, in hospital or on holiday, and may not have received the initial communication yet.
- Delivery of letters can take longer than expected due to postal delays.
- There may be a delay between the letter being printed and posted.
- The person may live in a rural area where post may take longer to be delivered.

For example, participants said:

## "Seven days is quite tight."

"I would like to see patients given more time – this needs to change."

## Issues with "resetting the clock"

The majority of participants also raised concerns about 'resetting the clock' to zero or removing the patient from the waiting list if they had not booked an appointment in the set timescale. It was felt there could be valid reasons why the person has not responded, and these should be taken into account. A person may not have responded because of, for example, health issues, physical disabilities, learning disabilities, or the cost of making a telephone call. Further circumstances that participants discussed around this included:

- When the person cannot, or finds it very difficult to, phone and make an appointment.
- When the person may need support to respond. This could be, for example, if the person finds it overwhelming to receive this communication and/or cannot understand the timeline.
- When the person hasn't received the communication(s) within the set timescales, for example, if the letter is lost in the post.
- When the person may be unable to phone during opening hours of the appointment system, for example, due to their own working hours and commitments or caring responsibilities.

When discussing this, participants highlighted the impact of this process, as well as the need to support people through it on a case-by-case basis, as there will be reasons why they haven't been in touch to book their appointment. As participants said:

"If someone has gone to the doctor and has requested to be put on the waiting list, they really need that help and support. For people who are not in contact with the service to make their appointment, there has to be a reason why they have not been in touch."

"It's also assuming that everyone is able to arrange their own appointments and some people aren't. Are they going to do this on a case-by-case basis?"

"On a 'bad' day it's almost impossible to think about planning an appointment and make sure people I need are available. Then receiving the reminder with the threat of being put back to square one is applying unnecessary pressure and anxiety."

Most participants felt that every reasonable effort should be made to contact the patient before resetting the clock or removing them from the patient list. Some participants suggested doing this by using more than one method of communication. For example, if a letter is used for the initial communication, an email or text message could be used for the reminder. Some also suggested phoning the patient as a follow-up if they have not responded to the initial communication or reminder. Participants explained, saying:

*"If possible they really need to use all three methods of communication mentioned (letter, email, text) to ensure they make every reasonable effort to contact the patient."* 

*"I don't think removing from the list is appropriate. I feel that in these few cases, a phone call would be useful or even a call to the GP for further advice."* 

"Clocks being reset to zero would just add to the extra workload. Also, people may have already waited months to hear about a possible appointment."

### Issues around communication and process

Participants discussed issues around communication and the process of booking appointments. They said that for Patient Focused Booking to work, the whole process needs to be clear and transparent. Communications need to be clear and easily understood by patients so they are well informed and know what is expected of them. One participant said they would like clarification of what is meant by *"removed from the list and returned to the GP"*. They felt that this implies they should wait to hear from someone, and asked what happens if they do not hear from anyone. They wondered in that case whether they would still be on the waiting list or would they have been removed.

Some highlighted that there should be flexibility in the system so patients who work can be offered early morning appointments if that suits them better. Some participants thought that retired patients are often more flexible and can at times find early appointments challenging.

Participants also noted the need for improvement, and learning to lead to change. They felt that the process would work well if every step in the process works but things could go wrong, and learning on this should be explored and implemented to improve.

## 4.3 Thoughts on "implied acceptance"

Participants were asked what they thought about "implied acceptance". This process takes place when an appointment is made by the health board on the patient's behalf and the information is sent to them. If no request for cancellation or change is received by the health board within 7 days of the appointment being issued, it is then assumed that they have accepted the appointment.

After a <u>brief explanation of this process</u>, participants shared their thoughts around "implied acceptance" and whether they thought the 7-day timescale is appropriate. Some participants expressed support for this, while others had concerns and issues – these were mainly around timescales and influencing factors that should be taken into account.

## Support for this approach

A small number of participants agreed with the 7-day timescale, saying that it is an appropriate process and amount of time, and they would be happy with this system. One participant felt that this was appropriate because they had used a similar system before and it had worked well. Another stressed that they felt 7 days was a reasonable timescale, but a flexible approach should be taken depending on people's circumstances.

## Concerns and issues: timescales and influencing factors

A large number of participants disagreed with the timescale, citing a number of reasons for this and suggesting alternative timescales. Many felt that the 7-day timescale is not appropriate, is too tight and not realistic, and some suggested timescales ranging between 10 days or a month, which they thought were more appropriate and realistic.

Participants discussed a range of reasons for this. Some explained that they would rely on family members or carers to support them in reading their letters, due to visual impairment for example, and that this could take time to do, making the 7-day timescale not appropriate for them. Similarly, several participants said that they rely on help from family members to take them to hospital and that this would take time to plan, saying:

## "I might need more time as I'd have to consult with a relative first to see if he's available to take me."

Echoing the reasons mentioned when discussing the timescales around Patient Focused Booking above, some highlighted issues around people being on holiday and missing the letter while away, or the impact of potential postal disruptions and delays due to strikes, which would mean that patients may not receive their letters on time. The participants felt that the 7-day timescale should be lengthened to take this into account.

Participants also felt that increased attention should be given to people in remote or rural communities when considering and agreeing timescales like this, suggesting:

"A sub-group should be set up to look at remote and rural situations for the Guidance, as people mustn't be forgotten. What impact does the Guidance have on remote and rural communities? For example, caring for elderly relatives, childcare cover or farming/croft (feeding the sheep) cover."

## 4.4 Preferred ways to receive information

When asked how they prefer to receive information about their appointments, participants expressed a range of views. These mainly highlighted the need to use a range of approaches

according to patients' preferences, as well as pros and cons around specific ways of communication, such as using letters, email, mobile texting, and telephone.

## A range of approaches according to preference

The key point discussed by participants was the importance of using different ways of communication according to people's needs and preferences. Many participants suggested that when being put on a waiting list people should be asked what their preferred method of communication is, and that this should be the primary method of communicating appointment information. One participant highlighted that:

## "There needs to be a variety of approaches used for getting the information out there, as everyone is different."

Asking patients for their preferred method of communication would ensure that no assumptions are made around what methods of communication people may prefer. For example, while some felt that some elderly people are less likely to use email or text messages, while others who considered themselves as elderly said they preferred, or at least were willing to, use these methods. This demonstrated that assumptions about communication preferences related to age, and any other reasons, should be avoided.

Several participants also said that they would like to receive information using more than one method. This would help to ensure that the person receives the information, especially if a supplementary method was used to follow-up if the person has not responded to the initial communication.

## Letter

Most participants said they would prefer to receive information by letter, and a few mentioned that they find it beneficial to have a paper copy they can easily refer to, for example by "pinning it on their fridge or noticeboard". Some participants also noted that services will often ask for a copy of the letter on arrival at the appointment. They said:

"(I would prefer to receive information) by letter, as this gives me something concrete that I can put in the drawer and hand over at reception and know that I'm not going to delete it accidentally."

"Because of the generation I am in, I prefer letters and paper, as it sits on my kitchen table as a physical reminder and I know when I am going to my appointment."

When communicating by letter, access needs were highlighted. For example, a participant who is registered blind explained that they would prefer to receive the information in braille,

if possible, even though a family member can read them the letter if needed. They explained:

"Some of these appointments can be quite private. You don't want anyone to be aware of them. It would be better that the individual could access and understand the appointment themselves."

Participants also noted the need for written material to be clear and easily understandable:

"A letter is good way to receive information, but it needs to be written in simple English with clear instructions if applicable."

This would also be the case for other forms of written communication, such as email and text discussed below.

## Email

Many participants said they would be happy to receive information by email. Some preferred this as the primary method of communication, and others would like this as a secondary method following a letter, text message or telephone call. A visually impaired participant said they would prefer to receive information by email, as that is the easiest method for them to read. Email communication was also discussed as an accessible way to change an appointment:

"We have a high level of deaf people as clients and they get worried about changing an appointment. Being able to email back to say it's not suitable would be more appropriate to them."

Challenges around communication via email were also discussed. It was highlighted that not everyone has an email account and some of those who do may rarely use it and not read the email within the proposed timescales. Another potential issue raised was about potentially needing to provide appointment confirmation in writing as part of the patient travel support process and when claiming back travel expenses. This could be an issue for anyone who isn't comfortable using email on their telephone, for example, or who does not have access to a printer to print out an email.

## Mobile text

Receiving information by text was another popular choice for participants. This was particularly the case as a secondary method of communication but also as a text reminder nearer to the date of the appointment: "It would be good to have a text reminder. Many people send reminders by text nowadays, for example your hairdresser and dentist, it's common so people are used to it. A text is good as a reminder."

For some participants a text message was regarded as not being accessible because of either not having a mobile phone or being unable to read the text message:

"I'm unable to read text messages unless they are very few words, again this is due to my limited vision. There will be other people in the same situation."

## Telephone

Communication by telephone was the least preferred method, with only a small number of participants saying they would prefer this. However, some participants explained that a telephone call can be helpful in certain circumstances, and it depended on the individual. For example, it was felt that a telephone call can be good for reaching a person if they have not responded to the initial communication. This could also be helpful in cases where it was an appointment being offered at short notice.

"Phone calls can be useful in some cases if there is short notice. Often the service will phone first to check the patient's availability then send out an appointment by letter, then you get a text reminder as well. With cancer treatment, appointments are fast-tracked and this happens and it works well."

Participants also thought that communication via telephone could be an appropriate way to communicate with patients that may have a low level of literacy, or people with learning disabilities, though they acknowledged that they may also need support from a family member, carer or support worker to understand and engage with the discussion over the telephone. There was some concern about potentially phoning a person who does not have English as their first language, as it may be more difficult for them to fully understand a conversation over the telephone.

# 4.5 Thoughts around being referred to a team rather than specific consultant

Participants were asked for their thoughts on being referred for treatment to a clinical team rather than a specific consultant. Current guidance allows patients who prefer to wait to be referred to a named consultant. This may be changing and in future everyone may be referred to a team rather than a specific consultant.

Participants had a range of views, highlighting both reasons to support this approach and change, as well as concerns and issues. These focused mainly on the potential impact on

people and specific groups, and factors that would be important to consider when taking this forward.

## Support for this approach and change

Many participants felt this proposal is sensible and that it would not affect them negatively. Their preference was to be seen as soon as possible, rather than waiting, and they recognised that in waiting for a named consultant there may be challenges around availability, linked, for example, with a staff member's annual leave and sickness, or emergencies and staff changes. They thought that there was a greater risk of disappointment when waiting to see a named consultant.

## Concerns and issues around this approach and change: potential impact on people and specific groups, and factors to consider

A greater number of participants, however, raised concerns about the impact of the proposal on patient choice. They felt that patients should continue to be able to choose to wait for a named consultant, as long as they are clearly informed that this will take longer compared to being referred to a clinical team. For example, one participant said:

## "I believe this choice should not be taken away from people provided that they understand that choosing a named consultant may mean a longer waiting time."

The importance of informed choice was highlighted, for example, for patients with long-term conditions or complex cases who feel they have been, or could better be, supported better by seeing a specific named consultant. The need for them to repeat stories and establish new relationships if changing consultants could lead to additional stress.

## "I personally wouldn't like to be telling my story every time I speak to a new consultant."

Participants suggested that consistency in seeing a named consultant could particularly benefit some specific groups. They discussed this being helpful for some older people, people with mental health conditions, people with learning disabilities and people who experience anxiety, as they would be able to establish trust in building a relationship with the specific consultant. The change, which would remove the option of choosing to wait for a named consultant, could, therefore, disadvantage these groups of people or those who could benefit similarly from consistency.

Whether agreeing or disagreeing with the proposed change, participants also raised key issues they thought were important to consider when taking forward this change and its implementation. For example, they highlighted the importance of good communication around available options and what patients could expect. Considering wider challenges, they

also noted the need for the correct specialism to be available in the first instance, whether delivered by a named consultant or by a clinical team.

# 4.6 Support needed when offered an appointment outside the local area

We asked participants what support patients may need to accept an appointment which is outside their local board area. This could be offered to ensure they are seen as quickly as possible, for example, through the National Treatment Centre (NTC) Programme<sup>4</sup>. They highlighted a range of support needs and important aspects that should be considered, such as transport and finance, personal and wellbeing support, communication and information needs, and time considerations. They also made it clear that these are relevant both when health boards are planning and booking the patient's first appointment, but also in considering whether the person would be expected to attend the same, further away, location for a follow-up appointment.

## **Transport and finance**

Most participants discussed the need for support around transport and travel. Participants explained that distance is a particularly important factor, as this could have a detrimental effect on the person's ability to attend an appointment at an NTC or in another board area. They also highlighted that people face significant challenges with transport in order to get to appointments and mobility issues were worthy of consideration, both for those who are disabled and non-disabled. They noted that accessible transport should be available for everyone, whether this is via public transport or provided through patient services.

Some participants highlighted concerns around financial support in relation to the NTC Programme. For example, unpaid carers may need to take time off work to support patients to attend an appointment further away, and this could lead to loss of income. Financial concerns were also linked to transport issues, as people may need to pay for transport or travel to attend an appointment which is further afield, and there are potential further costs involved, such as paying for overnight stays and needing to buy food during their journey and stay.

## Personal and wellbeing support

Participants noted personal and wellbeing support needs when potentially needing to attend an appointment further away. Some were concerned about having to ask carers or family

<sup>&</sup>lt;sup>4</sup> National Treatment Centres (NTCs) are a network of healthcare facilities across Scotland. NTCs provide extra capacity for planned inpatient care, day case treatment, and diagnostic services. You can find further information about NTCs on the relevant <u>NHS Inform webpage</u>.

members to support them to attend appointments which could be quite far away, as this would have an impact on the carer or family member. Needing to go further away for an appointment could also cause extra stress for some, due to needing to travel a longer distance, meaning more time is needed and there is a lack of familiarity. This could lead to needing more additional support. Some participants highlighted that patients' health and wellbeing needs should be considered before making an appointment on their behalf or asking them to attend an appointment at a different location. For example, they discussed how patients who are very ill, terminally ill, or in acute pain, should not be expected to travel far to be seen.

## **Communication and information needs**

Participants felt that communication and information around being offered an appointment further away needs to be improved. Clear, simple, and easy to understand information should accompany an appointment letter, to support people when attending an appointment further away. This should include a map of the location so patients know where to go, specific entrances and signs to look for, and information on the facilities available at the location, for example whether there are refreshments, as people will have travelled a long distance or their appointment may have been delayed. One participant said:

"I wouldn't want to be dumped at a hospital and be expected to find my way around."

#### **Time considerations**

Time was highlighted as an important consideration for travelling. For example, the time an appointment is scheduled for should take account of the time the patient needs to travel from their home to where the NTC is. Appointment details should also be sent with enough notice for people to plan their journey and arrange transport and potential carer support. An early morning appointment may not be suitable for patients with certain conditions. When booking an appointment for a patient to be seen outside their local area, all these aspects would need to be considered to support them to attend, otherwise they may simply not be able to attend their appointment.

## 4.7 Thoughts on the "reasonable offer" of appointment

Participants were asked their thoughts about the "reasonable offer" of appointments. The reasonable offer of an appointment was explained as one that, as a minimum:

- gives 7 calendar days' notice
- can be at any location across NHS Scotland
- the appointment details are provided in the way the person prefers and has agreed to, for example via email, and

• is before or after the Treatment Time Guarantee date<sup>5</sup>.

We briefly explained to participants that if the patient declines two reasonable offers, which meet the minimum criteria above, their waiting time clock is reset to zero, meaning they go back to the start of the waiting list. There would then be a clinical review where the person is either referred back to their GP or offered a further appointment if appropriate. Current practice also dictates that once a patient has agreed a reasonable offer of appointment, they can call to reschedule the appointment up to three times. The proposed change is to reduce this ability to reschedule from three to two times, and after that the person's clock would be reset to zero, following the process described.

Some participants did not understand the process as explained whereas many agreed with the change, at least in principle. Many discussed a range of concerns and issues around this approach and change, focusing on the need for clarity of language and process, need for understanding, flexibility and the importance of the person-centred "human" aspect, and further practical concerns.

## Concerns and issues with this approach and change

## Need for clarity of language and process

Despite a brief explanation, two participants said they did not understand the question and they felt that further clarity was needed on some aspects of the process. One explained that the meaning of "offer" and "minimum requirement" was not clear to them. This may suggest that the process and terminology used can be difficult to understand for some. Given that this process has significant and practical implications for individuals, it is important that the process is fully and clearly understood by all.

## Support for the approach and change

Many participants explained that they agreed with the change, reducing the ability to reschedule an appointment from three to two times before the patient's clock is reset to zero. For example, one participant thought that it is important that patients take responsibility for their appointments and try to avoid delays:

## "In my case I'd prioritise health over everything else but each to their own."

<sup>5</sup> After a diagnosis is made and treatment is agreed, each health board must ensure that patients receive inpatient and day case treatment within 12 weeks. This is called the legal Treatment Time Guarantee.

## Need for understanding, flexibility and the importance of the "human" aspect

Most participants emphasised the need for flexibility in the system. Many, even among those who agreed with the change in principle, argued that there should be a focus on individual circumstances. This could be, for example, if people cannot attend an appointment due to significant issues, such as caring responsibilities or other commitments already in place. One participant said, for example:

## "Patients have responsibilities."

Some said they disagreed with the 'automatic reset', and some felt that it is important for the NHS to acknowledge that waiting for an appointment could be an anxious time for people They highlighted that it is important to have a balance in the system between "corporate" and "human needs" to ensure fairness.

## Practical concerns: location and time, communication, and other factors

Some participants discussed the point about appointments potentially being anywhere across Scotland. They emphasised that it would be important for the appointment to be as close to home as possible, as transport and time can be key factors for people being able to attend. Some explained, for example, that because of the limitations of transport in their areas, it would not always be possible to attend an appointment and return on the same day, meaning they would need additional support.

Participants also highlighted the importance of good communication between the patient and the health board, and some explained that it would be helpful to receive a reminder 2 days before the appointment, as this would help avoid people not turning up.

When thinking about this process, one participant suggested that:

"The criteria for potentially penalising people with resetting the clock should ask 'are we able to fill this appointment?', 'did it waste clinicians' time and contributed to longer waiting times for everyone else?'"

This suggests that resetting the clock should not be directly tied to how many times an appointment was rescheduled. Participants thought that it should only count as declining a reasonable offer if the appointment was not able to be filled. For example, if the patient gives 3 months' notice of the change/cancellation then they should not be penalised.

## 4.8 Thoughts on "resetting the clock" for all patients

We then asked participants their thoughts on the policy of resetting the clock for patients on a waiting list (details on resetting the clock given in the <u>appendix question set</u>). This is currently done only for routine patients, and a proposed change would mean that this would be done for all patients, whether urgent or routine.

A small number of participants supported this change, and participants discussed concerns and issues. They suggested improvements and that resetting the clock should only be done for routine patients, and discussed how it could be seen as a negative and punitive measure.

### Support for this approach and change

A small number of participants agreed to the proposed change of resetting the clock for all patients, saying that everyone should have equal opportunities and people should take personal responsibility for their health.

### Concerns and issues with this approach and change

Participants discussed their concerns, with some expressing strong emotions about this.

### **Only for routine patients**

Some agreed that clocks should be reset only for routine patients, and not urgent care patients. They said that urgent cases may be a matter of life and death and could be too serious to allow further delay in treatment. Urgent care patients may also already suffer from mental health issues, they may already be feeling scared and anxious due to their condition, and resetting the clock would have a further negative impact. Participants also thought that urgent care patients are overall in greater need of support, as they may be unable to attend appointments themselves, needing support to do this. This could add a further aspect of complexity when arranging appointments, requiring the system to be a bit more lenient and understanding.

#### Resetting the clock seen as negative and a punitive measure

Many participants strongly opposed the idea of resetting the clock overall, expressing their anxiety and negative feelings about it, for example, by saying:

*"Shockingly awful"* "Terrible idea" "Absolutely draconian" "This is madness" Participants were also concerned that the proposed system would be "too robotic" and "not person-centred" and would not take into consideration personal circumstances, such as learning disabilities, mental health issues, caring responsibilities, or people's needs for assistance and support to be able to accept and/or attend an appointment. The general feeling was that patients should not be punished for something that may be out of their control. Participants said that if patients are asked to wait longer, their health may deteriorate further, both psychologically due to further distress from having to wait longer, and physically as their condition could worsen over time, leading to requiring more time and support from clinicians.

### Improvement suggestions

Participants discussed ideas on how to improve the proposed change and other ways to address the issue of missed appointments.

Some suggested introducing the proposed change through a trial period before rolling it out. Putting patients on hold until they get in touch rather than resetting their clock was also mentioned. A few people suggested resetting the clock only for people who have not given an explanation for a missed appointment, and not for those who provided a legitimate reason for not attending.

When considering the issue, participants highlighted that it is crucial to further investigate the problem of missed appointments, before moving to the proposed solution or resetting the clock for all patients, which many participants interpreted as "an unfair form of a punishment". They suggested exploring what the barriers are, what the NHS might be missing, and why people may really be missing the appointments, for example, whether a patient may be anxious about the appointment and need more support or has simply forgotten about it. Many felt that boards should make more effort to contact patients to make sure they are informed about appointments and are well enough to attend, and find out if they require additional support, especially in urgent care cases. Participants thought that identifying and addressing the reasons behind the issue should be the key to finding a better solution, which would benefit both the NHS and patients without involving punitive measures on either side.

Some also felt that practical difficulties in rescheduling appointments may pose a barrier to efficiency in managing waiting lists. A new, centralised, and easy to use system for rescheduling appointments could make sure people are not discouraged from rescheduling or cancelling appointments, which may currently be the case if people must wait on hold on the telephone for lengthy periods of time to reschedule their appointment. This links with comments in section 4.8, around barriers because of patients needing to phone during working hours, for example.

Clear communication was also discussed as a key aspect. Participants felt it is critical that boards communicate all relevant aspects of patients' care, including informing patients about whether they have been classed as urgent or routine. Participants said that they would also like to be informed about the consequences of missing appointments and any changes in their waiting time, for example, if they have been put back to the beginning of the waiting list, as also discussed in section 4.3.

## 4.9 Thoughts on "reasonable delay"

Participants were then asked their thoughts on reasonable delay and what impact this could have on them and the support they would need. A brief example of "reasonable delay" and the process was provided. For example, if there was a 30-minute delay in a clinic, and if the patient was unable to wait for the duration of it, this would be classed as a Does Not Attend (DNA), meaning their clock would be reset to zero. If the delay was longer than 30 minutes, which is the agreed reasonable delay, and the patient could not wait any longer, they would not be penalised and would be offered another appointment as soon as possible.

## Communication

Most participants felt that this would have minimal impact on them as long as they knew about this process and it was well communicated, including in accessible formats such as BSL. Many said that it would be helpful to know about how this works from the outset of their care, to help with journey planning. Some participants also thought that when patients arrive for their appointment, it would be useful to get an update on the current waiting time. This would help manage expectations and planning for return journeys.

## Fairness

Some participants discussed considerations around the fairness of the Does Not Attend (DNA) or Can Not Attend (CNA) classification, if the patient attended initially but could not wait for the reasonable delay. Participants felt that Can Not Attend (CNA) would be more appropriate for those who had presented for their appointment but been unable to wait for the full 30 minutes. Participants felt that showing compassion and understanding towards individual circumstances was important in such cases, and that the proposed process of resetting the clock should be adjusted to consider, for example, patients who may have pressing childcare responsibilities or strict travel times they need to keep. One participant said:

"[There] could be different reasons why a person genuinely can't wait longer, they should not be penalised."

## Support needs

Participants also considered specific support needs around reasonable delay. In thinking about actively waiting for their appointment while at the clinic, some noted that certain health conditions make sitting for long periods of time painful. Having cushions would be helpful, and patients should be supported to take regular walks during the wait period. It was also suggested that knowledge of one's current position in the queue could be helpful. They also noted that patients travelling from remote and rural areas may need to travel for longer periods and could have less flexibility than others around return journeys, so this should also be considered.

## 4.10 What matters most about Waiting Times Guidance

Participants were asked what matters most to them about the Waiting Times Guidance.

## **Communication and transparency**

The most prominent theme was communication and transparency. People most valued being provided with clear, accurate, and up-to-date information, and having continuous communication from boards.

Participants want to have advice on how to prepare for an appointment, timescales, types of support available, and advice on transport, as also discussed in section 4.1. Patients would also like to know what they can expect in terms of actual waiting time, to be notified about any changes to their appointment, including the reasons for potential changes. They would like to be regularly reassured that they are still on the waiting list and "not forgotten about", particularly if waiting times are awfully long. One participant highlighted the potential impact of a lack of communication:

## "When the NHS goes silent, that's when people can mentally spiral."

Participants would also like better communication around what might be their responsibility, and for the process to be explained clearly in the Guidance, in detail and from start to finish, to make sure there are no inconsistencies. A lot of participants felt that the responsibilities of the patient are unclear, for example, whether they should be more proactive or just wait for someone to contact them. As one participant said:

## "(It) has to be crystal clear what exactly is expected of me in this system."

Participants also discussed how the information should be provided, as also mentioned in section 4.1. They emphasised that information should be written clearly, in plain English, with terminology that is easy to understand and no acronyms, so that it is easily understood. Some discussed wanting information presented in a visual way to illustrate the process.

Many people mentioned the importance of being able to access information in a range of formats, such as braille or different languages, and to be offered further support, when necessary, for example, by providing an interpreter. This would make it easier, for example, for people with learning disabilities or dementia, to understand the information.

## *"From a visually impaired person's point of view, communication is number one."*

Participants noted that boards should never assume that people can access everything online and that they should aim to attach hard copies of additional information to letters of appointment or make them available at GP practices. Boards should also have correct contact details for patients, making it clear to patients whether they are defined as urgent or routine. There was also a call for boards to be more transparent in general in terms of waiting times so that the patients can access the information and see if there are improvements.

Participants discussed the need to increase public awareness around these processes. They said patients need to know that guidance around waiting times exists, as this would help them know their rights. Some participants felt that educating people and increasing awareness of missed appointments on the NHS would be beneficial, and patients could help tackle the issue.

Finding the right way to communicate with patients is also important. For example, this could be sending letters to some older people depending on preference but text messages to younger people, but this should not be based on assumptions but rather people's agreed preferences, as discussed in section 4.4.

Furthermore, as discussed previously in section 4.1, some mentioned wanting to receive more information about their actual appointment, such as how long the procedure is going to take, how long they are likely to be in hospital for, or what extra tests they will be going through. This is to help patients plan their day and prepare for the appointment so that it runs smoothly and no time is wasted. Participants also expected patients to receive a leaflet about support available, numbers to call and information about self-help.

More "human" guidance taking individual circumstances and needs into account

Participants discussed the importance for Waiting Times Guidance to reflect that boards should take patients' individual circumstances into account when developing and implementing such guidance and processes. For this to be achieved, guidance should be developed with patients and a subgroup could be formed to look at the changes proposed. One participant mentioned the use of Care Opinion to provide feedback when issues arise, and this feedback could be useful to consider when developing Waiting Times Guidance. Participants discussed examples of specific conditions and disabilities, such as dementia, and visual or hearing impairments, explaining that it can take longer to arrange a suitable appointment for people with such challenges, and that potentially more support is needed. They felt guidance should also consider patients' mental and physical wellbeing and the impact on this. Some participants were convinced that resetting the clock and not being kept up-to-date about one's progress in terms of waiting time can be detrimental to patients' health and wellbeing. Assurance that they can change or cancel appointments without being penalised would also be important to support patients' wellbeing.

Participants discussed further circumstances that need to be taken into consideration, such as living in a remote and rural area, or not having internet access, and characteristics like age, gender, or religion were also thought to potentially influence people's ability to arrange and attend appointments. They noted the importance of understanding the challenges people are facing, for example transport issues for people in rural communities, and how this can affect their ability to attend certain appointments. They emphasised that all patients should feel supported and should be offered:

## "(the) right care, at the right time, by the right people. Patients are not robots, guidance needs to be more human."

It was also thought that guidance could consider providing a certain "priority" to specific groups of people, for example NHS staff who need to return to work where there are shortages, veterans, carers, and urgent care patients.

Where the responsibility lies: patients, staff, boards and NHS

Participants discussed the significance of staff behaviours within this process. For example, the importance of staff being polite and attentive, with one saying:

## "I once had to wait for a long time for a procedure, but the nurse designated to me was so nice, I wasn't bothered about the wait."

It is also important that consultants are prepared for appointments by being up to speed with patients' medical history.

While participants were aware of the current pressures on the NHS, they believe that patients and boards have responsibility to work hard to improve the current situation. They suggested that guidance on this topic could include a section on patient responsibilities, for example outlining to patients the need to be more flexible and accept appointments at short notice if possible. One participant said:

"The guidance works both ways – patients have a responsibility too. Patients and staff to work together for everyone's benefit."

Participants also discussed the need for boards to update the current booking system as a priority, as they believed it could help to reduce waiting times. For example, they mentioned that having a more automatic system may make better use of cancelled appointments, offering them to other patients faster.

## Section 5: Conclusions and recommendations

This section contains the main conclusions drawn from this Gathering Views exercise and outlines recommendations.

## 5.1 Information needs while on a waiting list

When on a waiting list, participants highlighted the need to have information around the process, practicalities, available support and options. They also stressed that this information needs to be clear, up-to-date, appropriate and accessible. They would like to be kept informed throughout their waiting journey and to have a contact point to ask questions and inform them if their condition has deteriorated.

### 5.2 Patient Focused Booking

Nearly all participants agreed with the Patient Focused Booking process in principle and why it could be beneficial. They raised concerns, however, about the timescales discussed, asking for them to be extended. Concerns were also raised around resetting the clock, as it could disadvantage certain patients, highlighting the need for support on a case-by-case basis. Resetting the clock was seen as a harsh measure that should only be done if all other options have been explored. They explained they'd need to be well informed to understand the process and what is expected of them, while also highlighting that the process seems to be effective if every step worked smoothly in practices but things could go wrong.

#### 5.3 Implied acceptance

Some found the process around implied acceptance appropriate and reasonable, however many disagreed with the timescales discussed, as too tight and unrealistic. They highlighted the impact this could have on certain patients, their carers and support mechanisms, and how the process could go wrong in a range of circumstances, for example if someone was on holiday or there were postal strikes.

#### 5.4 Preferred ways to receive information

Participants highlighted the importance of using a range of methods when sending out information, according to patients' preferences. They discussed pros and cons for a range of communication methods, what they might be good for and what support patients might need to engage. The least preferred method was receiving information via telephone, though it was also seen as appropriate in certain circumstances, for example if an appointment became available at short notice.

### 5.5 Referral to a team rather than a specific consultant

Participants understood the proposed change to being referred to a team and potential risks associated with waiting for an individual clinician. However, they highlighted that this would limit patient choice and disproportionately impact individuals and groups that would benefit from seeing a named consultant, for example people with long-term conditions, mental health conditions, or learning disabilities. They noted the importance of good communication around options and what patients should expect.

### 5.6 Support to attend appointments outside local area

Participants discussed a range of support needed to help patients attend appointments further away, such as support with transport and finance, and personal and wellbeing support. Information on this would need to be communicated clearly and in an accessible way. They would also need to have clear information to help them attend the appointment, for example, where to go and what facilities are available once they arrive. They highlighted the need for time limitations to be considered when booking these appointments, recognising that patients from further away will, for example, need time to plan their journey and get there, so information should be sent out with enough notice.

#### 5.7 Reasonable offer of appointment

Some participants found the process around reasonable offer of appointment to be difficult to understand, highlighting the need for clearer and more accessible information to ensure that it is understood, both in terms of the process and the terminology. Many agreed with the change, reducing the ability to reschedule an appointment from three to two times before resetting the clock. However, most emphasised the need for understanding and flexibility, taking into account people's individual circumstances and support needs, and having a more "human" approach. They also noted the influence of a various factors on people's ability to attend an appointment or not, for example time and location and communication.

## 5.8 Resetting the clock for all patients

A small number of participants agreed to the proposed change to resetting the clock for all patients, routine and urgent. Some thought this was only appropriate for routine patients and not urgent care patients, as they have more significant and urgent needs, and resetting the clock would further impact their physical and mental health. Participants also saw resetting the clock as a negative and punitive measure, which is not considered to be person-centred and didn't take into account individual needs and circumstances. Participants discussed some suggested improvements, for example rolling out this stage through a trial period to assess impact, or only resetting the clock for those who have not given an appropriate explanation on why they missed their appointment. Exploring reasons behind why patients miss their appointments was also mentioned, as it would help identify and put in place the support people need and avoid missed appointments.

## 5.9 Reasonable delay

Most participants felt that this process was appropriate, as long as it was clearly communicated, from early in their care so they knew what to expect. Some discussed how to fairly classify patients if they have attended initially but could not wait for the duration of the reasonable delay, and the impact this would have. They suggested the process should take into account individual needs and circumstances, recognising that some may not be able to wait for valid reasons. Support needs were also highlighted when patients are expected to wait.

### 5.10 What matters most about Waiting Times Guidance

Communication and transparency were very important factors for participants. They wanted to understand what to expect in terms of their waiting journey and know that they hadn't been forgotten about. They felt that information on waiting times should be clear, easy to understand, accessible and in a range of formats, communicated in different ways. Participants also stressed the need for more "human" guidance that takes individual circumstances and needs into account, for example, their condition, what support they might need, their mental health and wellbeing, where they live and other characteristics such as gender or age. They also felt that responsibility around waiting times sits with everyone such as patients, staff, boards and the wider NHS, to ensure the process works smoothly.

#### Recommendations

The recommendations below are for the Scottish Government to take forward, working where appropriate with NHS Scotland, health boards and partner organisations.

#### **Recommendation 1**

Consider the range of information needs highlighted by the participants throughout this piece of work:

• Ensure that patients receive all required information around process, practicalities, available support, and options. This needs to be provided enough in advance and should cover their journey from start to finish.

- Ensure this information is up-to-date, clear, appropriate and accessible, and that it is provided in a range of formats according to patients' needs. Consider initially focusing on aspects that participants highlighted are complex and not as easy to understand, for example around the "reasonable offer" of appointments.
- Ask patients about their preferred communication methods and ensure these are used.
- Provide a contact point to ensure patients know where to go to ask questions including if their condition deteriorates.
- Ensure communication is open and provides opportunities for a two-way dialogue.

## **Recommendation 2**

Consider the findings in this report in order to improve the processes discussed in this report and communication around Patient Focused Booking, implied acceptance, referral to team rather than individual consultant, attending appointments out of area, reasonable offer of appointment, resetting the clock, and reasonable delay:

- Ensure timescales for the processes discussed are appropriate and take into consideration the needs and circumstances of individuals and groups. When mitigations or exceptions are in place, these need to be communicated clearly to patients.
- Ensure information around these processes and the terminology used is clear, easy to understand and communicated to patients appropriately, according to their needs.
- Ensure the processes are explained to patients further if needed, to ensure understanding of the processes and how they may affect their waiting journey.

## **Recommendation 3**

Ensure the development and implementation of these processes is person-centred and does not unfairly impact individuals and groups:

- Consider how these processes can be more "human" and person-centred, for example, by taking patient needs and circumstances into account, ensuring that measures are not perceived as punitive, and patients are aware of their responsibilities and options. This could be for example, providing alternative ways for people to reschedule appointments if they are not able or prefer not to do this via telephone.
- Continue working on Equality Impact Assessments (EQIAs) for each of the processes discussed, to identify impacts on different groups and people with different characteristics. Address these impacts through putting mitigations in place. Continue to review the Equality Impact Assessments (EQIAs) as needed.

• Health boards to review national EQIAs and complete local EQIAs to identify local impacts. Local EQIAs should be informed by local engagement with user groups around these processes, to ensure all patients are being supported.

#### **Recommendation 4**

Consider further exploring, at a local level, the reasons why patients miss or don't book appointments, in order to identify barriers for individuals and groups and put mitigations in place.

#### **Recommendation 5**

Ensure the processes and changes discussed in this work consider the 2012 NHS Scotland Charter of Patient Rights and Responsibilities:

- Consider how the patient rights and responsibilities outlined in the Charter are reflected in the processes discussed, and any changes required to ensure increased alignment.
- Consider working on increasing patient awareness and understanding around the Charter, including how information in the Charter is communicated and how this may be done more effectively to match the information needs outlined in recommendation 1, such as alternative formats. This work could include engagement around the Charter to identify with the help of users how it can best be used by patients and communicated, and how to ensure patients understand how Waiting Times Guidance is aligned with the Charter.

#### **Recommendation 6**

Moving towards implementation of the Waiting Times Guidance, the Scottish Government should liaise with NHS boards to ensure engagement is carried out with local communities to understand the changes that may directly affect them and their potential impact. This should be in conjunction with local Equality Impact Assessment (EQIAs).

## Section 6: Next steps and acknowledgements

- 6.1 This report has been shared with the Scottish Government. The findings will be used to help inform the development and implementation of the Waiting Times Guidance.
- 6.2 Healthcare Improvement Scotland Community Engagement & System Redesign will liaise with the Scottish Government to provide feedback to participants about how the views expressed in this report have been used.
- 6.3 We will use the learning and experience of this exercise including the equality monitoring information within our work to inform future methods of Gathering Views.
- 6.4 We thank everyone who took part and shared their experiences, thoughts, insights, comments and suggestions. We are incredibly grateful to the organisations who supported us to link with groups and individuals and for the time they gave us to discuss the issues covered in this report.

## Appendices

# Appendix 1 – The questions used in the Gathering Views exercise

#### Patient communication on appointments

1. The intention is to give patients as much useful information as close to being accepted onto a waiting list for treatment as possible in the form of a leaflet or facts sheet.

What information would you suggest would be helpful to patients to know once they have been accepted onto a waiting list for treatment?

#### Prompt suggested options:

- Explanation of a reasonable offer/a reasonable offers package.
- Consequences for missing appointments.
- What happens when a patient Does Not Attend (DNA) and Can Not Attend (CNA).
- "Waiting well" information and how to be ready for your appointment.
- Explanation that appointment can be anywhere in Scotland if clinically appropriate.
- Travel expenses being available from health board when being asked to attend an appointment out with their board of residency.
- Information for the point of contact in receiving service for patient.
- What to do if patients feel their condition worsens.
- Supporting materials around mental health.
- Other (please give details).

2. When patients need to arrange their own appointment, we send out a communication asking them to make contact and arrange their appointment. This is called "Patient Focused Booking".

Communication (e.g. letter, email, text) sent asking you to make contact to arrange appointment.

### ↓

Reminder sent 7 days after the original correspondence if no appointment made.

## A further 7 days is allowed after the reminder. If no response, case is sent for a review by the clinical team.

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Your clock will be reset to zero and you will either be removed from list and returned to your GP or offered another opportunity to make an appointment.

#### What do you think about this?

Prompt: would you suggest a different timescale?

3. When an appointment is made on behalf of a patient and issued to them, this is called "implied acceptance". When this happens, if no response has been received by the health board within 7 days of the appointment being issued, it is then assumed that the patient has accepted the appointment. See flow chart below.

You are issued a letter with an appointment made on your behalf.

If you do no respond to your Health Board following receipt of this communication, it is assumed that you accept this appointment.

You have 7 calendar days to contact and change your appointment.

What do you think about this?

Prompt: is this an appropriate amount of time or would you suggest a different timescale?

4. We are keen to find out how people prefer to receive information about their appointments.

What ways would you prefer to receive information?

#### Access to Services

5. When a patient is referred for treatment they are referred to a clinical team, rather than a specific consultant. However, current guidance does state that patients who prefer to wait for a named consultant, can do so.

We are suggesting that patients should no longer be able to wait for a named consultant as you would be referred to a team.

What are your thoughts on this proposed change?

6. Where possible patients will be seen as close to home as possible, however to ensure patients are seen as quickly as possible, patients can be offered appointments across Scotland, especially now with the introduction of our National Treatment Centre Programme. National Treatment Centres (NTCs) are a national network of purpose-built healthcare facilities across Scotland, created to help reduce inpatient, day-case and diagnostic waiting times which will provide capacity for thousands of additional planned care surgeries and procedures each year).

What support do you think patients would need to accept an appointment out with their local board area?

#### **Reasonable Offers**

7. A reasonable offer is an appointment which, as a minimum:

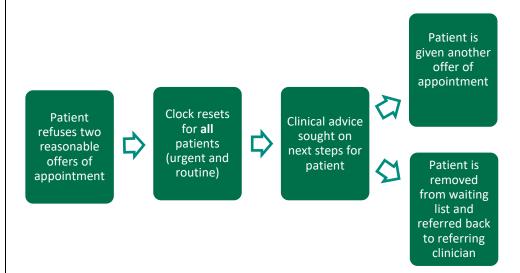
- gives 7 calendar days' notice
- can be at any location across NHS Scotland
- your appointment details are provided in the way you prefer and have agreed for example emailed to you, and
- can be before or after Treatment Time Guarantee date. (After a diagnosis is made and treatment is agreed, each health board must ensure that patients receive inpatient and day-case treatment within 12 weeks. This is called the legal Treatment Time Guarantee).

Health boards will however strive to make offers of appointment by way of best practice as follows:

- 14 days' calendar notice
- as close to home as possible
- have a reminder system in place for your appointment
- inform you of consequences of not attending your agreed appointment i.e. if you fail to turn up or cancel more than twice, and

• notify you of financial support if travelling out with your local area.

If you decline two reasonable offers (that meet the minimum requirements as listed above), your waiting time clock will be reset to zero which means that you will go back to the start of



the waiting list. There will then be a clinical review where you will either be referred back to your GP or be offered a further appointment if appropriate. See flow chart below.

If you do not attend your appointment and give no notice of this, your clock will be reset to zero, and you will go back to the start of the waiting list. The same process is then followed as above.

After you have agreed a reasonable offer of appointment, the current practice is that you can call to reschedule your appointment three times.

Proposed change is to reduce this to twice before your clock is reset to zero and same process applied as above.

Given what you now know about reasonable offers, what are your thoughts on this and the proposed changes?

8. Currently the clock is only reset for routine patients. What are your thoughts on resetting the clock for **all** patients, whether urgent or routine?

9. Clinicians do their best to keep clinics running to time, however would you consider 30 minutes a "reasonable delay" by the clinician to your scheduled appointment time?

For example, if you are unable to wait for the duration of the "reasonable delay" of a clinic (i.e. up to 30 minutes), this would be classed as a Can Not Attend (CNA), with your waiting time clock reset to zero.

If however the clinic runs more than the agreed "reasonable delay" (i.e. up to 30 minutes) and you could not wait any longer, you would not be penalised and would be offered a further appointment as soon as possible.

Prompt question: 'what impact could this have on you and what support would you need?'

10. What matters to you most about Waiting Times Guidance.

Prompt: this is not around appointments but about the Guidance itself.

Appendix 2 – Materials circulated to participants before the Gathering Views discussions



#### Gathering Views – Waiting Times Guidance

#### Background

Scottish Government has undertaken a review of the current <u>NHS Waiting Times Guidance</u> which was last updated in 2012. The Guidance will help to make sure that patients are managed fairly and consistently across the whole of Scotland while providing healthcare that is person-centred, safe and effective.

The aim is to provide clear, up-to-date and accurate guidance to support patients, their families and health boards. It should also be sustainable for the future delivery of services. The Guidance should be accessible for all, providing clear roles and responsibilities for both patients and health boards.

#### **Gathering Views**

<u>Healthcare Improvement Scotland</u> (HIS) has been asked to conduct a <u>Gathering Views</u> exercise to gather feedback on proposed policy changes being suggested as part of the review of the Planned Care Waiting Times Guidance. This will include the wording of updates/communications, as well as the changes themselves.

As of Tuesday 13 December 2022, Scottish Government have made a number of changes that have been approved by the Waiting Times Guidance Review group that includes representations from health boards, Public Health Scotland, Centre for Sustainable Delivery, other Scottish Government policy areas such as Primary Care and clinicians. Views are now sought from members of the public to help further develop the Guidance.

We want to speak to a range of people in terms of age, gender, ethnicity, and where people live. Your views are as important to us as everyone else's, so we want to speak with *you*.

#### The conversation

You will be invited to an <u>individual discussion</u> with an engagement officer from Healthcare Improvement Scotland. The conversation can be face-to-face, over the telephone or through an online platform such as Zoom or MS Teams. We will ask you some questions about how you feel about proposed changes. We will share the planned questions with you beforehand so that you have time to digest the questions and consider your responses.

During the conversation, we will be taking notes. Your responses will be analysed and captured in a report, which will be shared with the Scottish Government. Quotes may be used

to illustrate the main things that we've talked about. Quotes used will not contain the individual's name or job title, however, they will be associated with a particular group. Text may be edited to enable use in a variety of formats.

#### Do I need to take part?

Taking part is completely voluntary but we hope you will take the time to do so. This is a way of working with members of the public to help inform decisions about how care is provided – it really will make a difference to how we aim to deliver health and social care services in Scotland.

Even if you decide to take part, you can change your mind at any time without giving a reason. When talking about your experiences or when thinking about the interview afterwards, please tell us if you do not want us to include certain information.

#### **Equality Monitoring**

Equality monitoring information is being captured, including data relating to sex, sexual orientation, disability, age, religion and ethnic group. Providing this information is entirely optional. This information is to ensure we gather feedback from people from a range of backgrounds and contexts.

#### **Data Protection**

Healthcare Improvement Scotland comply with the Data Protection Act 2018 and GDPR 2018 when handling your personal information.

Any personal information about you will be treated as private and confidential and any identifying information you provide will be made anonymous in any published reports. Your information will only be used in this Gathering Views exercise and the resulting report. Your details will not be used for general marketing activities, nor shared with anyone outside Healthcare Improvement Scotland unless we have your permission or are required to do so by law. All personal information, written notes and related information, including this consent form, will be stored safely and in compliance with the Data Protection Act 2018. If you wish to see a copy of the notes taken during the discussion, please submit a sharing request to his.informationgovernance@nhs.scot . Please note that these notes will not be shared with you as a matter of course.

This discussion may be held over an online platform. Although we do not plan to gather personal information from participants, if you register to take part you must be aware that some companies transfer data to servers based in the USA and that any personal information you choose to share will be transferred to a country that does not provide the same data protection safeguards as the UK and EU.

For our full privacy policy, please go to www.hisengage.scot/privacy.

For more information about how we process your personal data, or if you have a concern, contact our Data Protection Officer at <u>his.informationgovernance@nhs.scot</u>. Alternatively, you have the right to complain to the ICO <u>https://ico.org.uk/concerns/</u>.

#### Get in touch

If you have any questions, please get in touch with your local Healthcare Improvement Scotland – Community Engagement office:

Name:

Email:

Phone:

Or you can contact Lisa McCartney, Area Manager (Community Engagement – North East Region), Healthcare Improvement Scotland by telephone 07823 447855 or by email <u>lisa.mccartney1@nhs.scot</u>.

### Appendix 3 – Equality monitoring data

#### Gathering Views equality monitoring results

#### Response rate

Equality monitoring questions, in the form of an online survey, were shared with the participants, either before or during the discussion. We also offered alternative ways to provide this information, via email or through a paper copy.

The form was provided to all participants electronically either during or following their participation. In some cases, the offices helped people to fill out the online form, i.e. asking the equality monitoring questions over the telephone and filling in the form on their behalf.

We received completed equality monitoring information from 58% of all participants who took part in this Gathering Views exercise (N=38).

#### Characteristics of respondents

Out of the 22 participants who completed an equality monitoring form:

- 86% were female and 14% were male.
- No participants considered themselves to be a trans person or have a trans history.
- 5% of respondents were aged 26-35 while 9% were 36-45. A further 32% were aged 46-55, 5% were aged 56-65 and 46% were 66+.
- All respondents under the age of 26 said they did not have experience of being in care.
- 27% considered themselves disabled and 73% said they did not.
- 14% used British Sign Language.
- 32% were unpaid carers.
- 95% were heterosexual/straight, with 5% preferring not to say.
- 24% had no religion, while 57% were Christian, 5% were Pagan and 14% preferred not to say.
- The majority (72%) had a white Scottish or British Ethnicity, while 5% each were Bangladeshi, Polish or Indian, 4% were Lithuanian, 4% German and 5% preferred not to say.

### Appendix 4 – Equality Monitoring form

#### About this Equality Monitoring form

We are capturing equality monitoring information, including data relating to sex, sexual orientation, disability, age, religion and ethnic group to ensure we gather feedback from people from a range of backgrounds and contexts. We want to understand how representative the people we talk to are.

You are not required to answer any questions you do not wish to answer. The information you provide is not linked to your name or any other personal details and will be kept anonymous.

- 1. What is your sex?
  - Female
  - Male
  - Prefer not to say
- 2. Do you consider yourself to be a trans person or have a trans history?

Trans is an umbrella term to describe people whose gender does not correspond with the sex they were registered at birth.

- Yes
- □ No
- Prefer not to say

If you answered yes, please tell us your preferred terms - e.g. non-binary, trans man, trans woman (optional).

- 3. Which age group do you belong to?
  - Under 16
  - 16-25
  - 26-35
  - 36-45
  - 46-55
  - 56-65
  - □ 66 and over
  - Prefer not to say

4. If you are under the age of 26, please can you tell us whether you have ever had any experience of being in care? This can include foster care/supported care, kinship care, residential care, looked after at home (supervision order).

- □ Yes, I have had experience of being in care
- □ No, I have not had experience of being in care
- Prefer not to say
- Not applicable

5. Do you consider yourself to be disabled?

(The Equality Act 2010 defines a disability as a physical or mental impairment that has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities. Substantial means the effect is more than minor or trivial and long-term means the condition has lasted or is likely to last 12 months or more).

- □ Yes
- □ No
- Prefer not to say

If yes, please include any more information you are happy to share:

- 6. Can you use British Sign Language (BSL)?
  - 2 Yes
  - □ No
  - Prefer not to say
- 7. Do you look after, or give any help or support to family members, friends, neighbours or others because of either:
  - long-term physical/mental ill-health/disability; or
  - problems related to old age?
    - Yes
    - □ No
    - Prefer not to say
- 8. Which of the following best describes your sexual orientation?
  - □ Bi/Bisexual
  - Gay/Lesbian
  - □ Heterosexual/straight
  - Prefer not to say
  - □ Something else. Please write in:
- 9. How would you describe your religion, religious denomination or belief?
  - Buddhist
  - Christian Church of Scotland
  - Christian Roman Catholic
  - Christian another denomination
  - □ Hindu
  - Jewish

- Muslim
- □ Sikh
- Pagan
- None
- Prefer not to say
- Other, please write in:

#### 10. What is your ethnicity?

- African, African Scottish or African British
- Arab, Arab Scottish or Arab British
- Bangladeshi, Bangladeshi Scottish or Bangladeshi British
- Black, Black Scottish, Black British
- Caribbean, Caribbean Scottish or Caribbean British
- Chinese, Chinese Scottish or Chinese British
- Indian, Indian Scottish or Indian British
- □ Mixed or multiple ethnic groups
- Dekistani, Pakistani Scottish or Pakistani British
- 🗆 Roma
- Showman/Showwoman
- □ White Gypsy/Traveller
- □ White Irish
- □ White British
- □ White Polish
- □ White Scottish
- Prefer not to say
- □ Other, please write in:

## 11. Do you usually have enough money each month to pay bills, buy the food, clothing and essentials you need and participate in your community?

□ Yes

□ No

Prefer not to say

12. Please use this space to tell us anything else you would like us to know about how you identify in relation to any of the above questions.

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You can read and download this document from our website. We are happy to consider requests for other languages or formats. Please contact our Equality and Diversity Advisor on 0141 225 6999 or email his.contactpublicinvolvement@nhs.scot

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