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your voice counts

# Gathering views on realistic medicine

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## Chapter 1. Executive Summary

- 1.1 In response to a request from the Chief Medical Officer, and as part of our Gathering Public Views activities, the Scottish Health Council gathered views from patients and members of the public on what realistic medicine meant to them. Realistic medicine means putting the person receiving health and social care at the centre of decisions about their care and creates a personalised approach. It encourages health and care workers to find out what matters most to patients so that the care of their condition fits their needs and situation. Realistic medicine recognises that a ‘one size fits all’ approach to health and social care is not the most effective approach for the patient or the NHS.
- 1.2 This report describes our engagement with the public and summarises the feedback and views we received. Their feedback provides helpful insights that will be useful for shaping health services and the way they are delivered in the future. In total, we organised 26 sessions and involved 228 people who represented a wide range of demographics and interests including:
  - older people
  - the general public
  - patient representative groups
  - people with mental health problems
  - people with a physical disability
  - people from ethnic minority communities
  - families on a low income
  - children and young people, and
  - travelling people.
- 1.3 In gathering the views on realistic medicine, we worked closely with 29 other organisations including local support groups, patient groups and associations, Third Sector organisations, charities, a school and local forums.
- 1.4 Essentially, we found that participants had a mixed understanding of what realistic medicine meant to them. A significant majority of people that took part in the group discussions had not heard of the term ‘realistic medicine’ before, however others had heard the term and some had a reasonably good understanding of what it means.
- 1.5 During the discussions, participants shared a range of ideas around what needed to change to make realistic medicine a reality.
- 1.6 Across the discussion groups, participants referred to putting the patient at the centre of service delivery as well as planning treatment and medications around the person in a way that was “having a partnership with patients”.
- 1.7 Participants said they felt that healthcare professionals needed to take a more holistic view of the patient i.e. by looking beyond the patient’s specific health condition and considering their wider circumstances.

- 1.8 Participants also spoke about the importance of building and maintaining trusting relationships with healthcare professionals. They felt that if realistic medicine was to become a reality then both staff and patients would need to put more effort into building that trust.
- 1.9 Many participants said that they felt there was a need to re-educate healthcare professionals in terms of soft skills (such as establishing trust with patients and interpersonal skills), person-centred care and communication
- 1.10 The importance of healthcare professionals listening to what the patient is telling them and using language that everyone understands instead of “jargon” was also highlighted by participants.
- 1.11 Most participants had heard the term ‘shared decision making’ although some did not understand what the term meant. The majority of participants felt ‘shared decision making’ was a better term than ‘realistic medicine’ – although some felt that each term had a slightly different meaning.
- 1.12 The feedback gathered from participants will be shared with the Scottish Government to help inform the ongoing discussions around realistic medicine and the future development of services.

## **Chapter 2. Background**

- 2.1 The Scottish Health Council was established in 2005 to promote Patient Focus and Public Involvement in the NHS in Scotland and to support the engagement of people and communities in the development of health and social care services. The Scottish Health Council is part of Healthcare Improvement Scotland, which seeks to drive improvements that support the highest possible quality of care for the people of Scotland.
- 2.2 In response to a request from the Chief Medical Officer, and as part of our Gathering Public Views activities, the Scottish Health Council gathered views from patients and members of the public on what realistic medicine means to them. Realistic medicine means putting the person receiving the health and social care at the centre of decisions made about their care. It encourages health and care workers to find out what matters most to patients so that the care of their condition fits their needs and situation. Realistic medicine recognises that a 'one size fits all' approach to health and social care is not the most effective path for the patient or the NHS.
- 2.3 This report describes our engagement approach and summarises the feedback and views we received from participants in sessions that were held during 2017. The views and feedback we received will be taken into account when shaping health services and the way they are delivered in the future.

## Chapter 3. Engagement Approach

- 3.1 The Our Voice<sup>1</sup> framework is based on a vision where people who use health and social care services, carers and members of the public are enabled to engage purposefully with health and social care providers to continuously improve and transform services. People will be provided with feedback on the impact of their engagement, or a demonstration of how their views have been considered.
- 3.2 A number of different organisations are key delivery partners for Our Voice including the Scottish Government, the Scottish Health Council, Healthcare Improvement Scotland, the Convention of Scottish Local Authorities (COSLA) and the Health and Social Care Alliance (The ALLANCE). The Scottish Health Council's Gathering Public Views methodology supports Our Voice by feeding public views into the heart of the development of policy and services. There are other examples of this available on the Scottish Health Council's website ([www.scottishhealthcouncil.org](http://www.scottishhealthcouncil.org))
- 3.3 The approach used by the Scottish Health Council was consistent with our normal Gathering Views practice in that it is not undertaken as formal research nor as a formal public consultation. The Scottish Health Council believes that gathering views via discussion with small groups of people is a particularly effective way of obtaining feedback. Our main consideration is about the quality of engagement as opposed to the quantity of people involved.
- 3.4 To gather views on realistic medicine, the Scottish Health Council organised discussion groups and engagement sessions in all 14 of the NHS territorial Board areas in Scotland.
- 3.5 The sessions were mainly small, facilitated discussion groups. We also spoke to members of the public at community events and arranged sessions as part of pre-arranged meetings of specific interest groups. The discussion groups were varied in nature with participant numbers ranging from less than 5 up to 25. These discussion groups were conducted using different engagement techniques and approaches and were specifically tailored to the participants taking part.
- 3.6 To encourage the discussions, we developed a set of predetermined questions – these are outlined in Appendix i.
- 3.7 In total, we organised 26 sessions and involved 228 people who represented a wide range of demographics and interests including older people, the general public, patient representative groups, people with mental health problems, people with a physical disability, people from ethnic minorities, families on a low income, children and young people and travelling people.

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<sup>1</sup>[www.ourvoice.scot](http://www.ourvoice.scot)

3.8 In gathering views on realistic medicine, we worked closely with 29 other organisations including local support groups, patient groups and associations, Third Sector organisations, charities, a school and local forums. Full details of all the organisations, together with the numbers of people we engaged with and the categories of people they represented are outlined in Appendix ii.

## Chapter 4. Feedback and Views

- 4.1 This section summarises the feedback, views and suggestions we received during the engagement sessions. Not every session answered all the questions as we wanted to tailor the engagement to ensure participants concentrated either on what was important to them or where they had views to offer. For example, some discussion groups only answered four or five questions whereas others answered all 16. Some answered the questions in full and other groups answered summarised versions of the questions (mainly for ease of understanding).
- 4.2 This report gives feedback on significant themes that were raised within the discussion groups and highlights where an important point was made from an individual group (e.g. where there were views that were either different from, or not raised, in the other groups). Where possible, quotes are included to support the themes that were raised in the discussions.

### Question 1

#### **We asked people if they had heard of the term ‘realistic medicine’ before.**

A significant majority of people that took part in the group discussions had not heard of the term ‘realistic medicine’ before being contacted by the Scottish Health Council. In half of the 26 groups no one had heard of the term ‘realistic medicine’. In those groups where someone had heard of realistic medicine, those people were in the minority. There were examples where participants had heard the term before such as in the discussion groups in Forth Valley and Lothian and in a young person’s group in Orkney.

### Question 2

#### **We asked people what the term ‘realistic medicine’ meant to them.**

There were varying responses to this question, ranging from no response (because the participant could not determine a view on what ‘realistic medicine’ meant to them) to a reasonably good understanding of the term. Unsurprisingly, given the number of people who had never heard of the term before, most people had little or no understanding or only some understanding of realistic medicine. Some examples of how participants described it include the following.

- “A type of medicine (homeopathic or different from alternative medicine, or a medicine prescribed by a GP rather than bought over a counter).”
- “Medication and side effects.”
- “Reviewing medication and reducing medication due to budget constraints or rationing.”

- “Patient expectations around their healthcare.”
- “Talking to patients and listening to their opinions on their healthcare – a partnership approach.”
- “Holistic care and general wellbeing.”
- “[Patients] having realistic expectations of the NHS and the NHS being realistic about what they can offer.”
- “It requires for the patient and the healthcare professional to sit together and look at the evidence, agree on a diagnosis and take it from there; it requires listing options, having a conversation about what is realistic and what might be right under the specific circumstances.”
- “Medicine that is specific for the illness being presented but also manageable and easy to maintain normal functioning... the side effects are not that chronic that the individual can’t maintain a normal life.”
- “Joint decision making – realism on both sides – doctor and patient.”

Below are some of the other ways in which participants described the meaning of ‘realistic medicine’.

<i>Spending a medical budget</i>	<i>Prioritisation – people knowing what to expect</i>	<i>Homeopathic medicine</i>	<i>Medicine you get at the chemist and not the doctors</i>
<i>Realistic expectations of the NHS</i>	<i>A kind of medicine, perhaps different from alternative medicine</i>	<i>Taking the patient’s view into account</i>	<i>Improved communications</i>
<i>An intent to integrate medical services and professionals into a unified approach</i>	<i>Not having a realistic expectation</i>	<i>Guarantees not kept</i>	<i>Accessible within a reasonable time</i>
<i>Influenced by TV, creating unrealistic views</i>	<i>Creating a feeling of entitlement with younger generation</i>	<i>Inappropriate treatment gives you longer, at any cost</i>	<i>Patient choice, but needs to be explained</i>
<i>End of life care, desire to die at home</i>	<i>Real actual medicine which is accessible to you</i>	<i>How we can run the NHS better and use resources more effectively</i>	<i>Concern that treatment should be evaluated on effectiveness not cost</i>
<i>Alternative therapies</i>	<i>Communication skills of the medical team</i>	<i>Lottery in terms of treatment</i>	<i>Speaking in a language that the patient understands</i>
<i>Making sure people know the consequences of the decisions they are making</i>	<i>Health options but possible cost savings and tailored to fit the patient</i>	<i>Less paternalism from doctors, more patient involvement in their own care</i>	<i>Listening to the patient more</i>

### Question 3

**We showed participants in the discussion groups a short video which described realistic medicine and then asked them what they thought it meant to healthcare professionals.**

There were a range of responses to this question, with some feedback similar to those described in the previous question. A significant overarching theme was communication, which was discussed to some degree by participants in all of the groups. Another common theme was that the term 'realistic medicine' has connotations with saving money and rationing healthcare as well as being considered by some participants as "an added burden to healthcare professionals".

#### *Communication*

Many participants said that they felt there was a need to re-educate healthcare professionals in terms of soft skills (such as establishing trust with patients and interpersonal skills), person-centred care and communication. They recognised, however, that a knock-on effect could be a need for longer appointment times.

#### *Listening and questioning*

Participants felt that realistic medicine meant listening to what the patient was saying and questioning what the patient needs and wants.

*"I think it's important to listen to patients and family because they [doctors, healthcare professionals] may be offering treatment that the patient doesn't want."*

*"It means that doctors will have to improve listening and other communication skills to take account of people's whole lives."*

In a discussion group comprising people from ethnic minorities, several participants agreed with the view that quite often people did not just want to see a certain GP but instead opted for an appointment with what was described as "the good GP". They said that this often led to a longer wait for an appointment and treatment as some GPs were regarded by patients as less effective listeners or less likely to help patients.

*"Health professionals need to listen to patients, who are experts about their own conditions. Some medics welcome the opportunity to have a conversation with their patients, but others believe they know best."*

*"It (realistic medicine) means that doctors will have to improve listening and other communication skills to take account of people's whole lives."*

A common theme from a few discussion groups was that using language that everyone understands instead of "jargon" was important for healthcare professionals and patients and in relation to realistic medicine.

*“Speaking in a language that the patient understands so that they are in a position to make decisions.”*

### *Person-centred care*

Participants across the discussion groups referred to putting the patient at the centre of service delivery as well as planning treatment and medications around the person in a way that was “having a partnership with patients”.

Participants said they felt that healthcare professionals needed to take a more holistic view of the patient i.e. by looking beyond the patient’s specific health condition and considering their wider circumstances.

Participants also raised the importance of staff working in partnership with patients and their families, with some emphasising the need to build trust with people. Participants also spoke about the importance of building and maintaining trusting relationships with healthcare professionals. They felt that if realistic medicine was to become a reality then both staff and patients would need to put more effort into building that trust.

*“A partnership with the patient, taking into account the needs of the individual and working out the circumstances. Not just giving out information but also giving the patient the opportunity to ask questions and giving them more responsibility for their own care.”*

*“Allowing patients to have a say in the needs and requirements in a safe and comfortable way, working closely with families, facilitating the needs of patients as much as possible.”*

Informing and empowering patients to make decisions about their healthcare, which included refusing treatment, was also a feature in the discussions. The following view was shared in a group which comprised young people:

*“Some patients may not want to know everything there is to know about their condition or treatment. This needs to be respected and people should be given a choice about what is discussed.”*

### *Realistic Medicine as an added burden to healthcare professionals*

Within a few groups, participants discussed whether some healthcare professionals could have the perception that realistic medicine meant an “added burden” to their job and the healthcare they provide. They were also concerned about any “added paper work” or that care could vary greatly from patient to patient and therefore add to healthcare professionals’ workload.

Participants agreed that some healthcare professionals would subscribe to the concept of realistic medicine and feel it was worthwhile; whereas others may feel it would not be the best use of time for various reasons including the following.

*“... it is extra paperwork or that it would be challenging to find the time for any additional work/training that may be required.”*

*“Some might not want to be questioned by patients or spend time on deeper, longer conversations.”*

*“More input, more work, more listening to patients perhaps.”*

*Realistic medicine being viewed as rationing or trying to save money*

Some participants discussed the possibility that healthcare professionals may fear that realistic medicine was about saving money.

*“Concerned that patients will expect more from the NHS but that there may not be the resources to fund patient ‘wants’.”*

*“It’s about health options but it could also be about cost saving and it should be tailored to fit the patient.”*

#### **Question 4**

**We asked participants whether they had heard of another term being used which is ‘shared decision making’.**

The majority of people in most groups had heard of the term ‘shared decision making’ although some did not understand what the term meant. In some groups, all or most of the participants had not heard of the term.

#### **Question 5**

**We advised participants that sometimes realistic medicine was also referred to as ‘shared decision making’ and then asked which term best described the discussion topic (i.e. ‘realistic medicine’ or ‘shared decision making’).**

The majority of participants in almost every group felt that that ‘shared decision making’ was a better term than ‘realistic medicine’ – although some felt that each term had a slightly different meaning. Some participants said that realistic medicine sounded more like “professional language” i.e. used by healthcare professionals.

Participants also said that they felt that the term ‘shared decision making’ also implied that the patient was involved in their healthcare and that there was an element of ‘teamwork’ when it came to treatment. However, a small number of people felt that neither term was particularly useful or meaningful to patients.

*“The term ‘realistic medicine’ is more of a professional term, I find ‘shared decision making’ is far clearer.”*

## Question 6

**We asked participants what they thought made a good doctor or healthcare professional.**

A significant theme to emerge from this discussion was that someone with good communication skills would make a good doctor or healthcare professional, particularly if they can listen and empathise with the patient and clearly explain the patient's condition.

Other feedback which was highlighted in the discussions included:

- giving enough time to the patient's concerns
- the patient having confidence in the healthcare professional's skills and expertise
- putting patients at their ease and making them feel comfortable, and
- being impartial, honest and not making assumptions about the patient.

A number of other points were raised during the discussion on what made a good doctor or healthcare professional. These included the following.

- Participants from the travelling community who said that a good healthcare professional gave "the right medicine at the right time". They also expressed the view that a good healthcare professional was "someone who gives you lots of medication or gives you every prescription you ask for".
- Participants from a discussion group which included people from minority ethnic communities who agreed that a good healthcare professional would be one who was more aware of cultural and religious issues when dealing with patients. They described this as an essential element when talking about realistic medicine.

## Question 7

**We asked people what were the most important elements or parts of a 'good consultation' with a doctor or healthcare professional.**

Whilst participants' responses were similar to Question 6, they also referred to the importance of good communication and listening to people, having enough time for the consultation and making people feel at ease.

Some other common themes were:

- giving information to patients for them to take away (e.g. a copy of the doctor's notes)
- ensuring the patient leaves the consultation with a better understanding of their health condition and knows how to take care of their own health
- not being asked to repeat information which has already been shared by the patient
- patients not having a long waiting time
- having transport available when it is needed and an acknowledgement that some patients have to travel long distances between home and hospital
- doctors following evidence-based guidelines, and

- patients being informed and clear about the pros and cons of treatment.

*“A good consultation constitutes agreeing what the problem is and jointly working out the treatment needed. Time with the health professional is needed in order for the patient to fully understand the treatment.”*

Some specific feedback was received from participants representing ethnic minority groups about the importance of being able to see a female doctor routinely and medical staff being aware of cultural issues, such as traditions, beliefs etc. They also highlighted the importance of ensuring patients could express themselves during the consultation and leave the appointment with meaningful and relevant information.

## **Question 8**

**We asked participants to think about a time when they were in a waiting room for a medical appointment, or sitting with the doctor, and asked them to describe how they felt. We also asked if there was anything that would have made them less anxious or feel more at ease.**

Generally, participants described feeling nervous or anxious whilst waiting for an appointment. Some said their level of anxiety very much depended on the reason for the medical appointment. For example, some said that they were more nervous or anxious when waiting for test results. Others said they became more anxious when there was a delay in the appointment, although they said they felt less anxious when they were told why there was a delay and how long they could likely expect to wait.

*“Appointment waiting times are important, waiting can cause a tremendous build-up of anxiety.”*

In terms of ways of putting patients at ease whilst waiting for their appointments, suggestions included providing background music, reading material or a TV in the waiting area. Some said that a comfortable physical environment was important (e.g. comfortable furniture) and an ambient temperature would also help.

Some participants highlighted the importance of a friendly staff attitude (for example, receptionists helping people feel relaxed before their appointments). Feedback from one of the discussion groups which was held in a remote and rural area was around the importance of confidentiality in a small community and the need to ensure that any conversations with the GP were not being overheard.

Some people felt that displaying multiple posters which showed lists of symptoms or “gory medical details” did not contribute to making a waiting area a comfortable environment.

*“I wanted nice magazines and posters to look at, not things with a list of symptoms to scare me.”*

Some other suggestions for making waiting areas more comfortable environments for patients included displaying posters which described mindfulness techniques or a leaflet/questionnaire which could be used by patients to gather their thoughts about why they were seeing the doctor and what they wanted from the consultation.

## Question 9

**We asked participants whether they felt able to ask their doctor about treatment or care options that were available to them. How comfortable do you think people feel, for example, when:**

### **a) asking a doctor for a second opinion?**

Most participants said that they would feel hesitant and uncomfortable in asking their doctor or healthcare professional for a second opinion. In most groups, a minority of participants felt that they would be comfortable, while all group participants in a session which represented older people felt that they would be comfortable in asking for a second opinion. One group comprising young people said that they would not feel comfortable in asking for a second opinion and a few others said it would depend on their relationship with the doctor, while some participants said that they were not aware that patients could ask for a second opinion.

Some of the reasons which participants shared about their reluctance to ask for a second opinion included:

- not wanting to offend the doctor in case it came across that the patient did not trust their judgement
- concern that the patient would be labelled as 'difficult'
- feeling more comfortable if the doctor was the same gender as the patient
- may adversely affect the doctor/patient relationship, and
- lack of an alternative professional opinion (such as in rural areas).

### **b) asking a doctor why they are recommending a specific treatment (or requesting no treatment)?**

The significant theme in this discussion was that participants felt confident about asking a doctor why they were recommending a particular treatment. Some participants said that questioning a doctor about a specific treatment would depend on the relationship they had with the doctor. Some participants felt that not everyone would have the confidence to question treatment options. Some young people said that they would feel uncomfortable about asking why a doctor was recommending a specific treatment – their reasons included that it depended on the person's age and younger people may feel less comfortable questioning a doctor.

### **c) asking for more information about their condition?**

The majority of participants were confident about asking for more information about their condition. Some participants said that it depended upon the extent of their knowledge of their health condition as they may look for information online first then go back and ask the doctor. A few participants in different discussion groups said they would be more comfortable asking a nurse for further information, rather than a doctor. Some participants thought that prompts from the doctor or healthcare professional would encourage people to ask for more information about their condition.

#### **d) asking to see a specialist or other healthcare professional?**

There was a mixed response to this question with some people reporting they would feel comfortable in asking to see a specialist, with broadly the same proportion of participants saying they would not feel comfortable. A small number of participants felt that it may depend on the relationship with the doctor or on the length of time they had had a particular condition (and especially if it was not improving over time).

*“Although I may want a second opinion, I would feel like I was being rude to ask. I would be worried the GP would think I was questioning their expertise, and I would feel very uncomfortable about that.”*

#### **Question 10**

**We asked participants if they would feel confident in discussing the benefits and risks of treatment options with the doctor or healthcare professional.**

The significant theme from this discussion was that participants in almost all the groups were confident in discussing the benefits and risks of treatment options with their doctor or healthcare professional. Some people clarified this by saying that they may need access to further information, for example a leaflet or online information before discussing any options. A small minority of participants said that they would not feel confident.

*“I personally do not have a problem with this and have had good experience of GPs and other health professionals but I know that a lot of people, particularly older people, find it very difficult to ask and might not feel confident about even knowing what questions to ask. However, so much is dependent on the attitude of the individual professional. Some do make it much easier than others.”*

If further information was required, participants stressed the importance of this being accessible to everyone, easy to understand and free from jargon and medical terminology. This was raised a few times in a discussion group which included people from an ethnic minority background.

#### **Question 11**

**We asked people whether they thought patients would always want to talk to a doctor about their treatment or condition or whether they would prefer to speak to a different healthcare professional (e.g. a nurse or physiotherapist etc).**

Around half of participants said they would prefer to see their doctor with the rest preferring to speak to different healthcare professionals. However, many participants (from both perspectives) said it would depend on their symptoms and conditions.

*“There might still be a general preference to see the GP first and then being referred. Personally, I’m happy to talk to, e.g. a pharmacist, physio or a nurse.”*

Other feedback included the following:

- Participants from rural locations emphasised that they only had access to a nurse practitioner so they felt they would not be able to see a GP even if they wanted to.
- Younger ethnic minority participants suggested that NHS24 could establish a social media service where people could ask questions about their healthcare rather than going to see a GP.
- Participants in a group which included people with a mental health condition said they were comfortable speaking over the telephone to a nurse practitioner.
- The option of self referral to other healthcare professionals and lack of awareness that patients can self refer.

## Question 12

**We asked people if there was anything that would stop (or limit) them from being fully involved in decisions about their healthcare and treatment.**

During this discussion a number of common themes emerged such as the following.

- A lack of time with the doctor or healthcare professional to discuss a patient's health condition in detail and gain a good understanding of how to manage their condition.

*“A lack of time in the appointment doesn't allow for more/extra information to be given.”* (from discussion in a group representing low income families)

*“... the barrier of time restrictions on appointments can make you forget to ask things.”* (from discussion in a group representing older people)

*“Time! It can be very difficult having a discussion with your GP if you have to be in and out in less than 10 minutes. This often prevents you from going into any detail.”* (from a discussion group representing older people)

- In many group discussions participants mentioned different types of barriers including language and difficulties when a person's first language was not English – participants said this could prevent them from being involved in decisions about their healthcare. Participants also said they had experienced the use of “complicated language” by healthcare professionals and participants in a group which included young people said they found “medical jargon” a barrier to understanding accessing health needs and understanding their condition and diagnosis.
- A lack of knowledge about a health condition which can lead to barriers regarding what questions to ask or patients 'downplaying' key or important symptoms. In a similar context, some participants described a lack of confidence as a barrier to asking more questions about their condition.

*“I do not have the confidence to question decisions as I do not feel I have enough information to have an equal conversation with my doctor.”*

Participants who had a physical disability, sensory impairment or learning difficulty said they experienced specific barriers which prevented them from being fully involved in decisions about their healthcare. For example, they described:

- instances where a lot of information was given to patients in print form which was difficult for people who were visually impaired, had learning disabilities or difficulties with reading and writing
- examples where negative staff reaction to their guide dog resulted in communication barriers
- some misconceptions from some staff about the mental capacity of patients who had a mental health condition, and
- examples of staff talking directly to people's carers (or key workers) instead of addressing the patient directly.

During the discussions, access issues were frequently highlighted as a barrier and included:

- having to wait too long to get an appointment to see a GP
- lack of access to a particular specialist or healthcare professional
- not having access to the same doctor each time a patient attends a consultation
- unable to get through when telephoning a general practice, and
- limited appointment availability.

In some discussion groups, participants referred to poor staff attitude as a barrier. One participant said that *"limited access to the mental health team and staff attitude"* stops (or limits) them from being fully involved in their treatment. It was mentioned in one remote and rural discussion group that *"people feel that they can't complain because this may affect treatment and how they are treated."*

### **Question 13**

#### **a) Does your doctor give you enough information about treatment and care options, including the risks associated with them?**

A small majority of participants said that their doctor gave them enough information about their treatment and care, however, a large minority said that they did not receive enough. Some participants said that this depended on the doctor or healthcare professional they consulted. Most participants stated that they did not receive enough information specifically about the risks associated with any treatment. The main examples given were around a lack of information about potential side effects of treatment and drugs and a lack of detail about further support that was available or where to get it.

*"The previous doctor would give me enough information, sometimes printing out NHS information or website links for me to look up. I found this very helpful."*

**b) Do you think the quality of information you were given could be improved in any way?**

Most participants felt that the quality of information they received from their doctor could be improved in some way. Suggestions included:

- increased access to 'easy read' versions of information and booklets
- signposting patients to Third Sector organisations that would have the time to provide quality information (for example Chest Heart & Stroke Scotland)
- more time available at appointments for doctors to provide information and feedback, and
- providing patients with written notes to back up what they are being told verbally (because it is not always possible for patients to recall all of the details).

**Question 14**

**Do you take any steps to make sure you understand the information, for example do you take notes during consultations or go prepared with a list of questions or say take a friend/relative along for support?**

Participants generally felt happy to see a doctor on their own and unaccompanied but some said they preferred to take a friend or family member along for support. They said that being accompanied was particularly important if they were getting test results and/or they were worried in some way about the outcome. Some younger people said they would ask a parent to attend with them and those with learning disabilities would normally ask a carer for support.

Most participants said that they would do some preparation before a consultation with a doctor or healthcare professional. Examples provided included making a list of questions to ask during the appointment or finding out more information about their condition either by reading leaflets or researching websites.

Participants in a discussion group which comprised people from an ethnic minority background said that they did not do anything to prepare for an initial appointment but if they went back for a second appointment they may look into what the healthcare professional told them previously.

*"I take a friend with me. It is good to have someone else there listening so they pick up on things I miss."*

**Question 15**

**As the population becomes increasingly older and more people have long term conditions patients can experience what is called being 'over treated' or they have medical and treatment plans which are too complicated and maybe not necessary. We asked people for their thoughts about this.**

Participants' responses to this question were quite diverse (this could be due to the complexity of the question).

A significant theme which emerged was that participants felt that 'over treatment' needed to be addressed and particularly in relation to prescribing and use of

medicines. There was a strong view from all participants that there needed to be regular reviews of patients' medication and that this should include aspects like the strength of the dose as well as the number of medicines and length of time being prescribed. One group felt that there was little consistency as to how different doctors prescribed medicine – they also felt there was a lack of consistency in prescribing geographically across NHS Board areas. However, some participants recognised that sometimes patients' expectations can put pressure on doctors to prescribe medication. There was discussion in one group about quality of life over life span with some participants mentioning their own personal experience of treatment and “... a *desire not to be over treated again.*”

*“Over medication is a huge issue – as parish minister I have regularly either helped clear through medicines in private houses or have advised pharmacists and/or GPs of situations that were clearly over medicated (multiple repeat prescriptions continuing long after the medication was needed).”*

There were discussions amongst participants about making sure the medicine or the treatment should be “made specific to the person”. This came out strongly in one of the groups which comprised young people. Some participants discussed the need for a more holistic look at patients' medication and in particular for people on multiple medications or those who had a long term condition(s). Participants in different groups expressed the view that doctors tended to treat patients' by “one condition at a time” and did not look at how treatment for one condition might affect treatment of another, or create side effects.

*“Health professionals never take a holistic view and they don't consider the impact of various medications.”*

A minority of participants felt that it was essential that patients receive all the investigations and medications they need and that a scan or test coming back negative should be regarded as valid in ruling out a condition and should not be viewed as ‘over treatment’.

Some participants also thought that ‘over treatment’ was not an issue and that patients were not seen by doctors and healthcare professionals often enough thereby leading to them receiving less treatment than they needed.

## **Question 16**

**We asked participants how they thought we can help patients from being ‘over treated’ or ‘over investigated’.**

Much of the discussion in response to this question was similar to the previous one with common themes emerging such as:

- a need to provide education and information about people's health conditions, including benefits and side effects
- encouragement of a patient-centred environment and a better understanding of what is important to the patient
- regular medical reviews – such as reviewing people's medication and treatment to determine whether it is still required, and
- better communication between healthcare professionals and patients.

*“Asking the patient if there is anything they would want or need as part of a plan. Incorporating work with charities, not just NHS, i.e. mental health therapy, home help, taxi service... the NHS and all the charities need to consult together regularly on an individual’s care and work out a treatment plan together. The only reason things seem over treated and over investigated is because there are so many different bodies working separately when there should be a system in place where it is one body working together.”*

## **Chapter 5. Next steps and Acknowledgements**

- 5.1 The feedback gathered from participants will be shared with the Scottish Government to help inform the ongoing discussions around realistic medicines and the future development of services.
- 5.2 The Scottish Health Council would like to thank all the participants who shared their views and considered what realistic medicine meant to them and their suggestions for improvement.
- 5.3 We would also like to thank the various organisations that worked with us in gathering views which ranged from NHS Boards, Third Sector organisations, voluntary groups, patient representative groups and other patient forums. We appreciated their support in making the engagement accessible and meaningful for all participants.
- 5.4 The Scottish Health Council will liaise with the Scottish Government in order to provide feedback to participants about how the views expressed in this report have been used.

## Appendix i: Discussion Questions

1. Have you heard of the term 'realistic medicine' before you came along today?
2. What does that term mean to you?
3. From what you have just heard, what do you think realistic medicine means to healthcare professionals?
4. We want to ask you if you have heard of another term which is 'shared decision making' before you came along today?
5. Sometimes realistic medicine is referred to as 'shared decision making'. Which term do you think best describes what we are talking about today – 'shared decision making' or 'realistic medicine'?
6. What do people think makes a good doctor or healthcare professional?
7. What are the most important elements or parts of a 'good consultation' with a doctor or healthcare professional?
8. Can you now think about a time when you were in a waiting room for a medical appointment or sitting with the doctor. Please can you describe how you felt? Is there anything that would have made you feel, for example, less anxious or more at ease?
9. We are interested in whether people feel able to ask their doctor about treatment or care options that are available to them. How comfortable do you think people feel for example in:
  - asking a doctor for a second opinion?
  - asking a doctor why they are recommending a specific treatment (or requesting no treatment)?
  - asking for more information about their condition?
  - asking to see a specialist or other health care professional?
10. Would you feel confident in discussing the benefits and risks of those options with the doctor or health professional?
11. Do you think that people always want to talk to a doctor about their treatment or condition or would they prefer to speak to a different healthcare professional?
12. In your experience, does anything stop (or limit) you from being fully involved in decisions about your healthcare and treatment?
13. Does your doctor give you enough information about treatment and care options, including the risks associated with them? Do you think the quality of information you may have been provided could be improved in any way?

14. Do you take any steps to make sure you understand the information, for example do you take notes during consultations or go prepared with a list of questions or say take a friend/relative along for support?
15. As the population becomes increasingly older and more people have long term conditions patients can experience what is called being “over treated” or they have medical and treatment plans which are too complicated and maybe not necessary. What are your thoughts about this?
16. How do you think we can help patients from being “over treated” or “over investigated”?

## Appendix ii: Summary of views gathered by location, category and number

Local Office	Category	In partnership with	Number of participants	Questions asked (Numbers 1 to 16)
Ayrshire & Arran	Older People	Kilmarnock Golden Age Group	7	1 to 15
Borders	General Public	Not applicable	7	All questions
Dumfries & Galloway	Older People	Not applicable	4	All questions
Dumfries & Galloway	General Public	The Usual Place (Social Enterprise Cafe)	25	1, 2, 6 and 7
Fife	Patient Group	Blood Borne Virus Forum	1	All questions
Forth Valley	Mental Health	Stirling & Clackmannanshire Mental Health Service Users Group	6	1 to 7
Forth Valley	Disability	Kinnections (people with Autism and Aspergers)	12	6,7,8 and 14
Forth Valley	Disability	People First (Learning Disabilities) Central Group	11	6 to 9 and 14
Forth Valley	General Public	Not applicable	2	All questions
Forth Valley	Ethnic Minority	Rainbow Muslim Women's Group	18	1, 2, 4 to 8, 12 and 14
Forth Valley	Disability	People First (Learning Disabilities) Alloa Group	8	6 to 8 and 12 to 14
Forth Valley	General Public	Forth Valley Royal Hospital	6	1 to 8, 12 and 14
Grampian	General Public	Not applicable	7	All questions
Greater Glasgow and Clyde	Ethnic Minority & General Public	Central & West Integration Network	6	All questions (summarised)

Local Office	Category	In partnership with	Number of participants	Questions asked (Numbers 1 to 16)
Greater Glasgow and Clyde	Ethnic Minority	Bangladeshi Association Glasgow	12	All questions (summarised)
Highland (in Argyll & Bute)	Public Representatives	Not applicable	2	All questions
Highland	Older People	Highland Senior Citizens Network	8	1 to 12, 15 and 16
Highland	Disability	Lochaber Disability Panel	11	1 to 10, 12 and 15
Lanarkshire	Low Income	Trinity Church Community Cafe, Hamilton	8	1, 2, 5, 5, 6, 7 and 9 to 14
Lanarkshire	Ethnic Minority	Larkhall Gypsy/Traveller community members	16	1, 2, 4 and 6
Lothian	General Public	Alzheimer Scotland	6	1 to 12
Orkney	Children & Young People	Kirkwall Grammar School Orkney Youth Workers Forum	12	1 to 14
Orkney	General Public	Voluntary Action Orkney	3	1 to 14
Shetland	Mental Health & General Public	Not applicable	8	All questions
Tayside	Young People	Police Scotland Youth Volunteers	10	All questions
Western Isles	General Public & Patient Group	North Uist Locality Planning Group Barra Locality planning Group North Uist Patient Participation Group Barra Cancer Support Group	12	All questions

**Total number of engagement sessions - 26**

**Total number of participants - 228**

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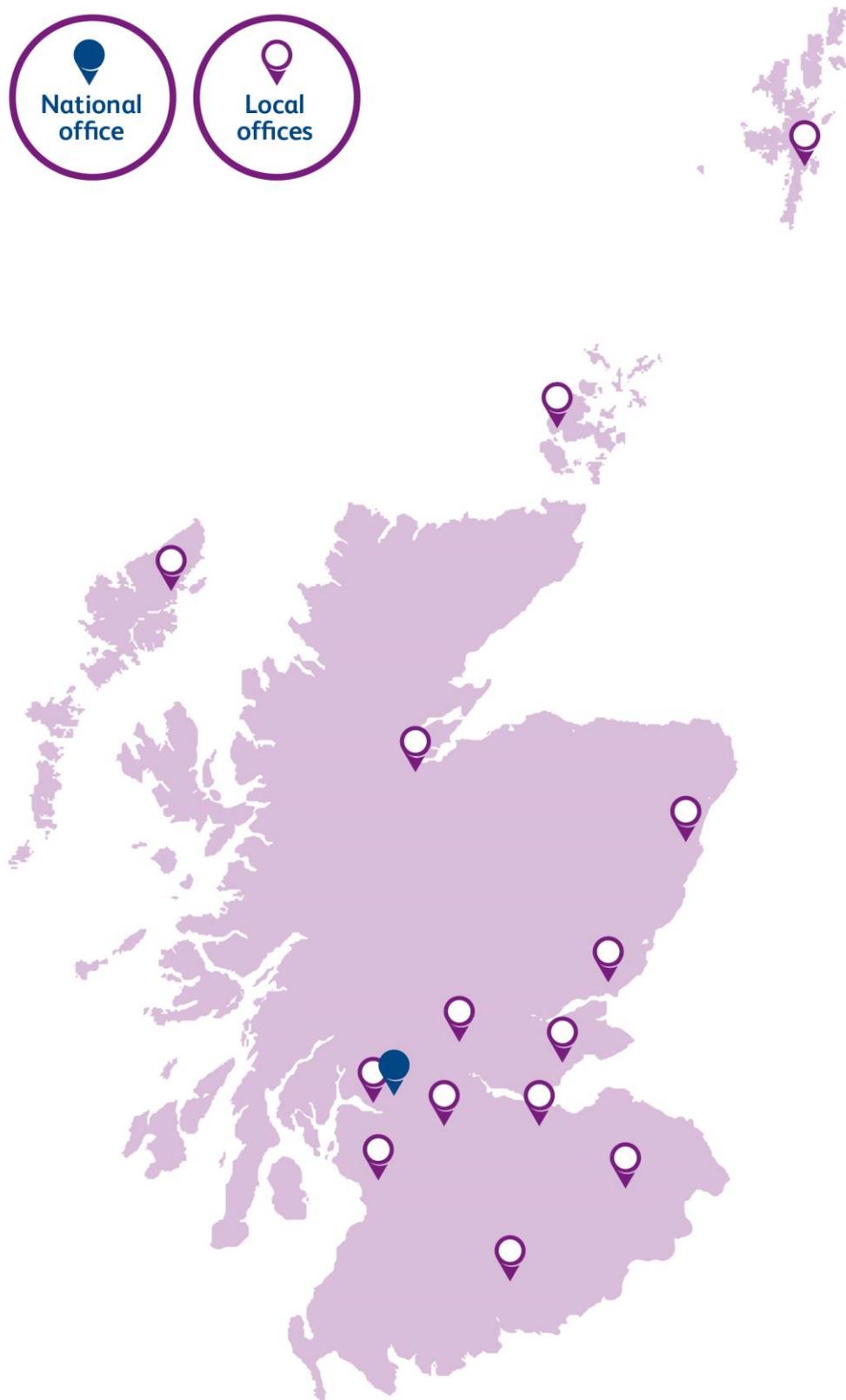
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