



making sure
your voice counts

The Scottish Medicines Consortium and public attitudes to the provision of medicines for the NHS in Scotland

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Foreword

We are delighted to publish this report of discussions with the public about how we decide which medicines should be available through the NHS in Scotland.

This area is one frequently fraught with controversy, and is of high interest to patients, carers and members of the public. It is important to state that this piece of work was not carried out as formal research, but as part of a broader programme of public engagement, and we were keen to find out what the public thought about the process we follow, and also how members of the public felt it best for them to be involved in future work.

There are no easy answers to some of the questions, and there are a range of views held by the public, which is hardly surprising. However, this exercise, carried out in ten discussion groups across Scotland involving nearly 100 people, demonstrates that the 'discussion model' approach is an effective way of enabling members of the public to participate and provide their views on complex issues, and the findings from this exercise will be invaluable in providing ideas and suggestions for how we take things further. This report will be used by the Scottish Medicines Consortium to influence its thinking about its future development.

There is a real commitment by the Scottish Medicines Consortium, Healthcare Improvement Scotland and the Scottish Health Council to explore and engage with the public further on these matters, and these discussion groups have got us off to an excellent start. Our thanks to staff in both the Scottish Medicines Consortium and the Scottish Health Council for their work in conducting these discussions, and especially to those members of the public who freely gave of their time to contribute their views.

Richard Norris
Director, Scottish Health Council

Anne Lee
**Chief Pharmacist, Scottish
Medicines Consortium**

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Focus group leads: Colin Suckling - SMC Public Partner, John Dally - SMC Public Partner, Helen Cadden - SMC Public Partner, Scott Bryson, Sandra Auld - SMC Patient and Public Involvement Group members.

Introduction

The Patient and Public Involvement Group (PAPIG) of the Scottish Medicines Consortium requested the support of the Scottish Health Council to convene a number of discussion groups across Scotland to engage with members of the public about the work of the Scottish Medicines Consortium and the provision of medicines in the NHS in Scotland. The purpose of these discussion groups was to:

- engage with the public to explain the role of the Scottish Medicines Consortium in relation to access to medicines within the NHS in Scotland
- explain how patient and public opinion is brought into consideration in discussions and decisions about medicines and medicine use within the Scottish Medicines Consortium, and
- learn from participants about their understanding of and expectations for the provision of medicines in the NHS in Scotland.

Process

In total, 94 people participated in ten discussion groups which took place across Scotland between November 2013 and June 2014. The numbers of participants at each group varied with three being the minimum and 16 being the maximum.

Each discussion group focused on a target population – these were young people, people of working age, older people, people from a black and minority ethnic (BME) background, people living in a remote/rural setting, people living in a lower income area, people associated with involvement structures within the NHS, carers, users of mental health services and people working within the Third Sector. While it was acknowledged that this list was not exhaustive, it was felt that the audience would give a representative sample of the general population.

The Scottish Health Council local offices which hosted one or more discussion groups were Ayrshire and Arran, Forth Valley, Greater Glasgow and Clyde, Lothian, Orkney, Tayside and the Western Isles. The geographical spread of the discussion groups ensured a good mix of both urban and rural representation. Some of the comments relating to the discussion questions are listed in Appendix 2.

Each discussion group followed the same format and lasted approximately two hours. Each group had members of the Scottish Medicines Consortium in attendance to discuss their work and answer any specific questions participants had. Scottish Health Council staff were in attendance to facilitate and record the discussion. All groups started with a presentation which outlined the role of the Scottish Medicines Consortium and set the scene for the discussion.

Participants were then asked to discuss the following five questions.

- Should NHSScotland assess the value for money of new medicines?
- Should NHSScotland treat all disease areas/patient groups equally?
- Are there any situations where NHSScotland should be prepared to pay more for a medicine?
- What role should the public have in the decision process concerning the availability of new medicines?
- What would you like to know about the Scottish Medicines Consortium's recommendations about new medicines in Scotland? How would you like to receive this information?

Where time permitted, participants were also asked to review and comment on the briefing note currently used by the Scottish Medicines Consortium to share information about their advice.

A report from each individual discussion session was produced by the Scottish Health Council and this was shared with participants to ensure factual accuracy.

Feedback from Discussion Groups

Some of the comments relating to the discussion questions are listed in Appendix 2. Summarised feedback on each of the discussion questions is noted below.

Q1. Should NHSScotland assess the value for money of new medicines?

There was general agreement across all ten of the groups that NHSScotland should assess value for money. Various reasons were given, some related to general principles of money management – “this has to be considered as part of general housekeeping” and “cost does matter”. Others related to the nature of the NHS – “our health service is publically financed” and “if we want to keep the NHS there is a requirement to do this”.

Two of the groups, whilst accepting the principle of assessing value for money, focused their discussion on other matters related to this issue. In the Older People's group there was support for the statement that at the end of the day “patient outcome is the main factor” (a view echoed in the Carers group discussion). The Older People's group discussion also qualified the support for assessing value for money by stating that “There are times when governments need to increase their budget”. In the Young People's group, participants qualified their support for assessing value for money by stating that a variety of medicines are required to treat people and that therefore the process of approving medicines for the NHS in Scotland could not simply be about “saying that one drug is better value than the other”. In the discussion in the Young People's group information was also an important topic with participants commenting that patients and the public don't have enough information about the costs of treatments and what money is spent on – this topic was also picked up in some other groups with the NHS Structures group calling for consideration of “the broader costs, both with and

without a particular medicine”.

Lastly, the Young People’s group debated the comparative merits of spending resource on a limited life extending medicine as opposed to preventative measures and concluded that money that is invested in medicines that only prolong life for a limited time might be better invested in prevention, or in medicines that would be more likely to cure a condition.

Q2. Should NHSScotland treat all disease areas/patient groups equally?

This question generated the largest number of comments from the discussion groups. Across all of the groups there was widespread support for an NHS which would "treat all groups equally" in the sense that everyone would get the best medicines available even if that means higher treatment costs for certain groups of patients. However support for this view was qualified in the Working Age group, with statements such as "treat everyone equally but look at the quality of the result".

In just over half of the groups there was comment that equal treatment meant putting resources into other types of treatments (not just medicines) particularly for patient groups not related to cancer or other life threatening diseases. In the Carers group there was comment that treating groups equally involved taking prevalence into account and on that basis more mental health medicines needed to be made available in the NHS.

In four of the groups there was debate whether NHS treatment should be withheld in cases where patients had contributed to their ill health by making unhealthy lifestyle choices. In the Young People’s group a consensus was reached around the need to treat people equally regardless of their lifestyle.

Consideration of this question led to some participants in three of the groups arguing the case for priority to be given to children and parents with young families (Mental Health, Working Age and BME groups). Related to this discussion there was also a call within the Older People and Working Age groups to consider the economic impact of returning younger people/large numbers of people to health/economic productivity when weighing up whether or not to treat all disease areas/patient groups equally.

Q3. Are there any situations where NHSScotland should be prepared to pay more for a medicine?

There was fairly widespread support for the concept of there being situations where NHSScotland should pay more for a medicine with comments such as "cost of medicines shouldn't matter" and "give patients the choice".

However in four of the groups (Working Age, Mental Health, Remote & Rural and BME) the "yes" was qualified by consideration of such matters as the efficacy of the medicine, a desire to give priority to medicines for children, "if it saves money in the long run" and "if it controls severe pain".

There was debate in several groups (Working Age, Older People, Lower Income and

Third Sector) around quality of life versus extension of life with a number of comments highlighting that extension of life on its own was not felt enough to justify paying more; quality of life issues were felt to be important factors to consider. In addition the NHS Structures group felt that quality of life should be given greater weighting for young people however they made the point that “ethical decisions should not be completely based on age”.

In a number of the groups there was debate concerning the use of resources. In the Young People's group a scenario concerning a drug which would only extend an individual's life for three months (at a cost of £30,000) produced arguments for and against taking the drug. In the Older People's and Carers' groups similar scenarios produced support for utilising the resources to help other patients. In the Remote & Rural group there was general support for the need to evaluate the cost-effectiveness of medicines.

In terms of the specific situation where NHSScotland should pay more for a medicine, the Carers group highlighted that more money should be spent on cancer treatments. In the Mental Health group there was concern expressed that not only was there a lack of research money for mental health medicines but it was also felt that new medicines are given to disease groups which had the most powerful advocates and loudest voices.

Q4. What role should the public have in the decision process concerning the availability of new medicines?

Participants were very largely supportive of the public having an input into the decision-making process but there was some debate about this in half of the groups. In the Older Age group there was comment that patient interest groups should be able to express views but not to influence professional decisions. This view had resonance in some other groups with a similar comment in the BME group concerning charities. The reason for this view seemed to centre on the public's lack of technical knowledge (Third Sector group) and the potential for bias from public/patient contributors (Working Age and Carers groups).

In some of the groups there was a call for Scottish Medicines Consortium to let the public know that they can be involved (Working Age and Rural & Remote groups) but the bulk of recorded comment under this question was in the form of suggestions as to how the Scottish Medicines Consortium might encourage and improve patient and public involvement in its decision-making process.

A number of the suggestions concerned the Scottish Medicines Consortium meetings. Three of the groups (Young People, Carers and NHS Structures) called for the meetings to be more open for interaction with members of the public. They suggested that the meetings should include a public question and answer session, there should be more time in the run-up to meetings to allow public input, and that the meetings should be geographically accessible. In addition the BME group called for more general interaction with the public via the continuation of the current programme of discussion groups.

The topic of widening the general reach of the Scottish Medicines Consortium led to

calls from some of the groups to use existing patient or public groups, whether they already be in organised form (NHS Structures and Young People's groups), or patients contactable via a clinic (Carers group) or discussion groups called together by organisations such as the Scottish Health Council (Older People's group). In some discussion groups it was proposed that the Scottish Medicines Consortium utilise NHS professionals such as GPs and pharmacists (Carers and Working Age) to promote or enable involvement or even advocate on behalf of patients who were not getting their voice currently represented (Mental Health group). Finally, the Young People's and NHS Structures group encouraged Scottish Medicines Consortium to make use of social media, newspapers and local radio to let people know about the work of the organisation and the opportunities to get involved.

Q5. What would you like to know about the Scottish Medicines Consortium's recommendations about new medicines in Scotland? How would you like to receive this information?

Most of the comments recorded against this question consisted of suggestions about other ways to receive information about the Scottish Medicines Consortium's recommendations beyond the briefing notes currently placed on their website.

Four of the discussion groups suggested that the Scottish Medicines Consortium utilise NHS staff/premises by displaying information in GP surgeries (Lower Income and Older People's groups), in pharmacies (Older People's group) or by utilising health information screens in health centres (Young People's group). The Mental Health Group commented that GPs could be better informed about the Scottish Medicines Consortium and its work.

For some of the groups (Older People, Working Age and BME) ensuring that the Scottish Medicines Consortium briefing was available in a variety of formats - plain English, other languages and audio version - was an important issue. A number of groups (Older People, Lower Income, BME and Mental Health) encouraged the Scottish Medicines Consortium to try and get information/good news stories out through traditional forms of media such as newspapers, television or centres for community information such as libraries. A few groups (Young People, BME and Mental Health) suggested use of social media including YouTube.

Finally, there were a few suggestions about what should be in the Scottish Medicines Consortium's briefing document. The NHS Structures group wanted more detail around why a decision had been made in particular relating that information to patient outcomes evidencing that patients were at the heart of the decision making process. The Working Age group suggested that the briefing should include reference to brand names of medicines and give evidence as to how to pronounce the often complex medicines names.

Evaluation

Participants at each discussion group were asked to complete an evaluation following the event. In total, 80 people completed an evaluation form across the ten discussion groups. All participants provided positive feedback, with 98.4% of people who answered

the question 'how would you rate this event' rating it as good or very good.

A common theme that emerged from the feedback was specifically the quality of information provided during the session and how it had greatly improved attendees' knowledge of the Scottish Medicines Consortium; in particular what the Scottish Medicines Consortium does and the processes surrounding the approval of newly licensed medicines for use in NHS Scotland. Feedback gathered identified that for the most part the discussion groups were felt to be very inclusive of everyone who attended and respectful of individual needs. We received repeated feedback stating people felt listened to and that the presenters from the Scottish Medicines Consortium actively listened and answered questions with honesty and as little medical jargon as possible.

When asked 'what did you value most' one of the biggest takeaway points was the excellent level of knowledge imparted and in particular how it was presented; not as a large block of data to try and digest but in a manner conducive to learning. Generally, participants expressed a desire for more time to be spent on the matters arising and called for the meetings to be longer to better get to grips with the complex moral issues. Some of the groups were larger than others and in some of those groups participants felt numbers limited the range of discussion.

Overall the attendees found the sessions engaging and interesting, which was reinforced in the final section of the evaluation where the usefulness of this event was highlighted but also a strong desire to see similar future ones take place. This desire to be kept informed of Scottish Medicines Consortium activities and future public engagement was highlighted.

Next Steps

We would like to thank all of the participants who contributed to the discussion groups and the staff within the Scottish Health Council and Scottish Medicines Consortium who supported this project.

This report and the reports from each discussion group have been shared with the Patient and Public Involvement Group of the Scottish Medicines Consortium for their consideration and to inform their future workplan.

Appendix 1: Discussion Groups facilitated by Scottish Health Council staff

Target Group	Discussion Group
Young People	Discussion session took place with 10 senior school pupils from Clydevew Academy, Gourock on 27 November 2013.
Older People	Discussion session took place with 11 people of older age on 27 April 2014 in Dundee.
People living in a Remote/Rural setting	Discussion session took place with 8 people who lived in a remote or rural setting on 1 May 2014 in Harris.
People of Working Age	Discussion session took place with 9 people of working age from a range of professions on 6 May 2014 in Glasgow.
Carers	Discussion session took place with 11 carers on 9 May 2014 in Glasgow.
People associated with NHS Involvement Structures	Discussion session took place with 10 people who are involved in NHS structures on 20 May 2014 in Edinburgh.
People from a lower income community	Discussion session held with 16 people from St Mary's Over 55s Group, Dundee, on 9 June 2014.
People who use Mental Health Services	Discussion session took place with 7 people from the Mental Health Services Public Reference Group on 10 June 2014 in Irvine.
People working within the Third Sector	Discussion session took place with 9 people working and/or volunteering within the third sector on 11 June 2014 in Kirkwall.
People from a Black and Minority Ethnic (BME) community.	Discussion session took place with 3 people from differing BME communities on 11 June 2014 in Stirling.

Appendix 2: Feedback and Comments from Participants at Facilitated Discussion Groups

The following section summarises comments and feedback from participants.

Q1. Should NHSScotland assess the value for money of new medicines?

Young People

- “Money that is invested in drugs that only prolong life for three months might be better invested in drugs that would be more likely to cure a condition.”
- “Money should be invested in prevention.”
- “It is not about saying that one drug is better value than the other; it is about knowing the facts and knowing that there is a variety of drugs that can treat a person depending on their condition. Therefore, it is hard to put a value on new medicines as you need a big variety to treat people.”

Older People

- “Costs do matter and funds need to be used efficiently. However, at the end of the day, patient outcome is the main factor. As population increases it will become more costly so the government needs to increase their budget.”
- “Costs do matter and throwing money at something can’t always solve a problem but there are times when governments must be asked for more money. We know budgets are finite and it’s a fine balancing act. Would not like to be in the shoes of those making these decisions.”
- “Don’t want to deprive people but there is a fixed budget and this needs to be taken into account.”

Remote and Rural

- “The group agreed that value for money for new medicines should be assessed.”

Working Age

- “Who else would be taking this decision if it wasn’t as is now? Could it be a politician and if so would the public trust them to carry out this role appropriately?”
- “Our health service is publicly financed and this means that the public should have a say in how it is run.”
- “There was consensus from all participants that everyone was supportive of assessing the value for money of new medicines. Participants highlighted that if we want to keep the NHS, there is a requirement to do this.”

Carers

- “Yes, however you have to be clear by what you mean by the term 'value'. Value is not just the cost of the medication but the treatment and impact on the quality of life of the patient and carer.”
- “Have to look at the impact on individuals and specific costs associated with need.”

NHS Structures

- “Yes, as we have to recognise that resources are not infinite. Maybe it requires a change in the system around how we fund the NHS.”
- “Need to consider the broader costs, both with and without a particular medicine.”

Lower Income

- “Yes, they should assess the value of drugs.”
- “Could the NHS in Scotland not reinstate charging for prescriptions to help cover costs?”

Mental Health

- “Yes, as cost does matter.”
- “There has to be a health body that evaluates treatments.”
- “Overall, the group agreed that value for money needs to be assessed.”

Third Sector

- “The group agreed that it shouldn't matter where a person lives - availability of drugs/treatments should be the same anywhere in Scotland.”

BME

- “The NHS knows what they are doing – we should just accept it.”
- “There is a danger that cost comes as a priority before effectiveness, people think that cost always comes uppermost.”

Q2. Should NHSScotland treat all disease areas/patient groups equally?

Young People

- “Often people just seem to be given pills to cope with a condition when there are other ways they could be helped. An example was given of a person who participants knew was being prescribed pills for depression and not offered any other approaches to manage the condition. This means that some people are not treated equally as they are just given pills rather than looking at the person overall to treat the underlying problems.”
- “One person asked if emphasis should be given to those with rare diseases.”

Although it may cost a lot on a treatment that benefits only a few people, that person is still equally important.”

- “It is also important to treat people not just through medicines but to spend money if it is appropriate on other services like physiotherapy.”
- “Need to ensure individual needs are met so that people are treated equally.”
- “If people have a condition due to their lifestyle choice, should they be given the same priority as others who have a condition that was completely out with their control? The group felt that you need to treat people equally regardless of what their lifestyle is.”

Older People

- “Although with rare diseases there are less people to treat and so medicines can be more expensive, patients with these illnesses still want to be treated.”
- “Everyone should be treated equal and get the best treatment available even if it costs more money.”
- “With, for example cancer, a person’s life expectancy may dramatically increase with medication but with other, non-life threatening illnesses such as mental health, life expectancy is not the issue.”
- “Treat people equally.”
- “Important to treat rare diseases the same as others.”
- “From an economic point of view, if there are lots of people with a particular illness that can be treated and cured, then they go back to a lifestyle where they are earning, supporting family, paying taxes etc and so there are wider issues to consider than just the cost at the time of medication.”
- “Worry that if long term economic benefit is a main factor, that this could have a negative impact on elderly and disabled people.”
- “Quality of life for the patient is important.”
- “A patient may not want another six months of poor quality life.”
- “It should not be dependent on age but instead, needs to be a mix of things.”
- “Elderly people may not have the same opportunity to discuss their medication options with their doctor.”

Remote and Rural

- The group discussed illnesses that have sometimes been identified with remote and rural settings, e.g. depression. The group agreed that all disease areas and patient groups should be treated equally and not discriminated against, even with respect to lifestyle.
- “Cancer is serious, but so are other conditions.”

Working Age

- “Treat everyone equally but look at the quality of the result?”
- “If one was to ask a person over 70, they would probably opt to give priority to the young.”
- “Living well is important. There is a need to consider the cost saving by keeping people in their own homes.”

Carers

- “Morally all should be treated equally but sometimes some groups do take priority based on cost and effectiveness.”
- “How long it takes to develop a medication may affect how people are treated but the commitment should be the same.”
- “There needs to more medications to treat mental health as a significant percentage of the population experiences this and it is not always a priority in terms of NHS spending.”

NHS Structures

- “The profile of different diseases is different, therefore, there may need to be a difference in the way they are treated.”
- “There should be equality of care; discrimination between different patient groups shouldn’t happen.”
- “Maybe more should be spent on prevention.”
- “End of life and orphan diseases should be dealt with differently.”
- “Patients should be considered as individuals – opportunity for biomedically specific medicines.”

Lower Income

- “If it’s your family member with a rare disease then you would want treatment for them.”
- “Will the NHS not just have to ask the politicians for more money?”
- “It seems unfair that people can get access to medications depending on where they live e.g. some medications available in England and not Scotland and vice versa.”

Mental Health

- One participant stated that as they smoked they felt that they had done damage to themselves and therefore did not think that they should be prioritised for a smoking-related disease over a person who has a disease that was not their fault. The same participant also felt that as they were older and had no family that they shouldn’t be prioritised over people such as parents who have a young family. There was disagreement in the group about this point of view.
- “There are life threatening conditions but there are also lots of other conditions which can have a huge impact on a person’s quality of life, which should be considered when looking at costs.”
- “Family circumstances should be considered for whether a person gets a drug that would otherwise not be given to the general public due to cost.”
- “If you consider that every person is important then someone with a rare condition should get the same chance as everyone else for a medicine that will help.”

Third Sector

- “Sometimes people born with certain conditions can’t help their needs; this similarly

applied to people who are dependent on alcohol and drugs. Therefore it's not fair if they are discriminated against."

- "Lifestyle choice comes up a lot and moral ethics – it's difficult to judge one person's needs over another and it can be a moral dilemma."
- "Cancer has a high profile, but more people die of other conditions."

BME

- "What is equal? You can't say everyone is equal. It all boils down to cost – everything is about cost, but cure should be a priority – not cost."
- "Yes, if a new medication saves just one life it should be bought."
- "It all matters on how it improves the quality of life."
- "Who are we to judge what value someone has, who take priority and if they are treated equally?"
- "Those undergoing end-of-life care should be made comfortable, even if it costs lots."
- "I would rather have the money spent on medication to keep a child alive than an older person."
- "Children have to be the priority every time."

Q3. Are there any situations where NHSScotland should be prepared to pay more for a medicine?

Young People

- "Cost of medicine shouldn't matter."
- The cost of medicines are not explained to people and it is not something that we should be concerned about, as it is about making people better regardless of cost.
- "The cost of medicines is something that should be well budgeted for to make sure that drugs are available."
- "It's not fair to look at the average life expectancy that someone with a new drug might get. For one person they might live an extra year and someone else might only live three months, so it is not possible to take a meaningful average and work out how much more you are prepared to pay for a medicine."
- "If you know the price of the drug you were getting and that you were only going to live for an extra three months, you might want to give the £30,000 it would cost to treat you to someone else."
- "If a drug was to prolong my life by an extra three months, then I would consider this time to be very precious and I would take the extra time the drug would give me."

Older People

- "If it will cost a lot of money to give someone a very short time and yet many operations/treatments could be carried out with the same money, the greater good of more people may be better use of resources."
- "Extension of life is not the only factor to take into account e.g. sometimes surgical treatment may be too traumatic for that patient."
- "Don't just assume that everyone wants to live another six months even with

poor quality of life. Need to discuss with patient individually.”

Remote and Rural

- “All decisions pertaining to the choice of medicines must be carried out with humanity and take into consideration the social impact it will have.”
- “Have to be realistic as there is not an endless pot of financial resources.”
- “The Scottish Medicines Consortium must carry out its duties dispassionately and fairly, same as GPs/Clinicians need to use their experience and common sense.”
- “The group strongly agreed that the treatment of children should be a priority when it comes to prescribing medicines.”
- “Alternative to not prioritising treatment of children is an example of families seeking treatment abroad.”
- “Recognition that there is a limited budget and therefore very hard to make final decision at times.”

Working Age

- “If it improves a person’s quality of life.”
- “Providing a medicine which keeps people out of care/hospital may be more expensive in the short term but it could save more money in the longer term.”

Carers

- “Yes e.g. cancer treatment.”
- “Yes, but this should have common sense attached e.g. if a large amount of money is required only to prolong life for a few months there is a need to consider quality of life. Also will someone else suffer at their expense?”
- There was some discussion on general concerns from GPs about over prescribing. It was highlighted that Community Pharmacists have a changing role and they can offer support regarding medications. One participant reported the positive support received from his Pharmacist.

NHS Structures

- “Quality of life should be given greater weighting for young people. Nevertheless ethical decisions should not be completely based on age.”

Lower Income

- “Quality of life and extension of life are two different things.”
- “Give patients the choice.”
- “Quality of life is most important.”
- “Wouldn’t want extension of life if the quality of life is very poor.”
- “There is a lot of waste with medication. Could cut back waste by prescribing fewer tablets at a time.”

Mental Health

- “Yes, at times they seem to find the money when they need to.”
- “Yes, if the medicine meets expectations.”
- “There should be more research money put into medicines for Mental Health as at present this is not an area getting much attention for developing new treatments.”
- “It often seems that those who shout the loudest are given a new drug which might be very expensive, which is worrying for those groups of patients who don’t have advocates to make a case for them.”

Third Sector

- “The quality of life is very important, as opposed to just extending life. Extending life may just be prolonging the person’s suffering.”
- “Some people just don’t want medicines.”
- “It should be based on a person’s personal decision every time, if they want to try medicines to prolong their life, access should be given.”

BME

- “If it’s a cure.”
- “If it saves money in the long run.”
- “If it controls severe pain and in end-of-life care.”

Q4. What role should the public have in the decision process concerning the availability of new medicines?

Young People

- “If you have meetings open to the public, then I would go along to watch but I would like some way to feed my views into the meeting.”
- “Information about this could be put into newspapers and social media could be used to inform the public as much as possible.”
- “In order to reach the largest number of people, engage with patient groups who can filter the information down to individuals.”

Older People

- “Individuals should have as much opportunity to be involved as patient groups.”
- “There is a place for focus groups with patients who are not necessarily part of a patient interest group. This could be arranged through forums such as the Scottish Health Council who could bring people together. “
- “Patient interest groups should be able to express views, but not to influence professional decisions.”

Remote and Rural

- The group strongly felt they should be able to make a contribution to the work of the Scottish Medicines Consortium.
- Suggestion was made that a representative from the remote and rural communities be involved with the Scottish Medicines Consortium.
- The group were very interested in the work of the Scottish Medicines Consortium but felt it needed to be publicised more.

Working Age

- “It is good that people can submit information on the website.”
- “The public often have a vested interest in themselves, their families etc.”
- “Pharmacists could get more involved in promoting this.”
- “The public need more awareness of how to get involved.”

Carers

- “Public voice is important.”
- “Public can have an emotional response to the topic. The Scottish Medicines Consortium needs to be objective but decisions have to be made in wider context. The Scottish Medicines Consortium need to engage with the public who may need some support to remove the emotion behind the assessments but the benefits to this would be a more rounded process.”
- “Terminology and language is a barrier.”
- “The 18-week period for the Scottish Medicines Consortium process may mean added pressures and that decisions being made are not well rounded – could you allow more time for public input?”
- “The form seeking feedback could also be sent to GP surgeries.”
- “Most long term conditions have specific clinics – could people not be targeted through them?”
- “Participants expressed concerns that experiences may not be passed on by a charity.”
- “Could you use social media to make people aware of the assessments – it was noted that there are positive and negative aspects to this.”

NHS Structures

- “There needs to be more meetings in public; the public needs to be able to ask questions. The public meetings should be geographically accessible across Scotland with leaflets and publicity to raise awareness of the opportunity to be present at meetings.”
- “The meetings need to be more open so that questions can be responded to, perhaps a 10-minute session at the end. It is also important to show how comments are given consideration for future implementation.”
- “Local radio could be used to spread information across the country.”
- “Process needs to be more collaborative.”

- “If the public are to be more involved in the decision-making process a mechanism needs to be developed to support this and time added in to ensure this is effective.”

Lower Income

- “Individuals also being engaged with by the Scottish Medicines Consortium and not just engagement with patient interest groups.”

Mental Health

- “Having voluntary organisations submit Patient Interest Group submissions seems like a good way forward.”
- “GPs and consultants should have a role to speak for patients who are not getting their voice currently represented.”
- “Carers need to be involved in the process as at present they don’t seem to be involved.”

Third Sector

- “Sometimes the public don’t know enough about it and can’t say good or bad as they don’t have medical knowledge.”
- “Having a public voice is important and it’s your right to have a say.”
- “You don’t want to be the one to make the decisions – leave that to the health professionals.”
- “The government wants a stronger patient voice in Scotland.”

BME

- “You can never get decisions from discussions from members of the public but everybody has the right to have a say, nobody should be declined this option.”
- “Charities should be more involved in the decisions on whether a new drug is accepted. They should be allowed to speak and to voice their opinion and present their cause to the rest of the committee but they should continue with not being allowed to have an ultimate vote.”
- “The best way for the public to be involved is to do what you are doing and come out for meetings with groups.”

Q5. What would you like to know about the Scottish Medicines Consortium’s recommendations about new medicines in Scotland? How would you like to receive this information?

Young People

- “Before today I had no idea how long it takes to make a drug and doubt that others will have a clue either so more needs to be done to involve the public.”
- “Didn’t know until today that the Scottish Medicines Consortium had a website

or existed.”

- “The 18 weeks it takes to approve a new medicine seem like a long time and especially if it is not approved at the end of the process. Need to give the public more information on the decision-making process, especially with regards to the timescales.”
- “Information about the Scottish Medicines Consortium could be put up on health screens to get information across as at present these screens in health centres are very under used and tend to just show the news on them.”
- “The Scottish Medicines Consortium should get a YouTube channel as that is where a lot of people search for information these days.”

Older People

- “People would like to have a better understanding of the work of the Scottish Medicines Consortium.”
- “Would like the information in alternative formats, not just online. Many people don’t use or have access to the internet.”
- “Get good news stories out into the public domain e.g. through newspapers, TVs and libraries.”
- “Continue holding discussion groups and meetings such as this one today in order to widen the public’s knowledge of the Scottish Medicines Consortium.”
- “In order to raise public awareness of the Scottish Medicines Consortium, it would be good if the briefing note was available in public libraries, GP surgeries and pharmacies.”

Working Age

- Comments on the Scottish Medicines Consortium briefing note included:
 - “It would be helpful to pronounce the name in the heading.”
 - “Include the brand name as opposed to the full name.”
 - “Produced it in different formats.”
 - “Could include an audio version on the website.”
 - Include elsewhere rather than just on the Scottish Medicines Consortium website?”
- “Would like the details on the official website.”
- “Individuals could register interest in certain conditions/types of medication and receive updates accordingly.”
- Regarding attending Scottish Medicines Consortium meetings which are now open to the public, it was highlighted that if these are only held during the day then that could be a barrier to many members of the public.

NHS Structures

- “Would like to know more detail around why a decision is made. Detailed information together with summaries for patients about the Scottish Medicines Consortium’s decisions are given on their website. This is recognised but this is not always helpful for those that have poor or no access to IT.”
- “It would be good to know more about outcomes for patients – evidence that patients are at the heart of the decision-making process.”

Lower Income

- “Display Scottish Medicines Consortium information in doctors’ surgeries, e.g. updates on the Scottish Medicines Consortium’s work.”
- “Sending information (for example questionnaires) to local voluntary sector umbrella organisations for further dissemination to groups and individuals on their large contacts databases, and asking for feedback. This would be a way of getting a wider range of public views.”

Mental Health

- “Website is very easy to get information from.”
- “Need to advertise wider when a recommendation is made. Could the Scottish Health Council local office network be used?”
- “Social media could be used to get messages out.”
- “Need to ensure that GPs are up to date about new recommendations and the role of the Scottish Medicines Consortium. One example was given of a GP not knowing who the Scottish Medicines Consortium is.”
- “Would be good if you could get the papers and the news to report on all the decisions that are made and not just the drugs that have been rejected.”

BME

- “Not everybody has access to the web; it would be good if we could see it in the paper.”
- “If it is on a website is this translated into other languages so we can read it? If not, it should be.”
- “The process as to how new medications are passed needs to be more widely known. For example on the website, on a YouTube video and in plain English so everybody can understand.”
- “Social media is a good outlet for younger people, I don’t really use it. But younger people would.”

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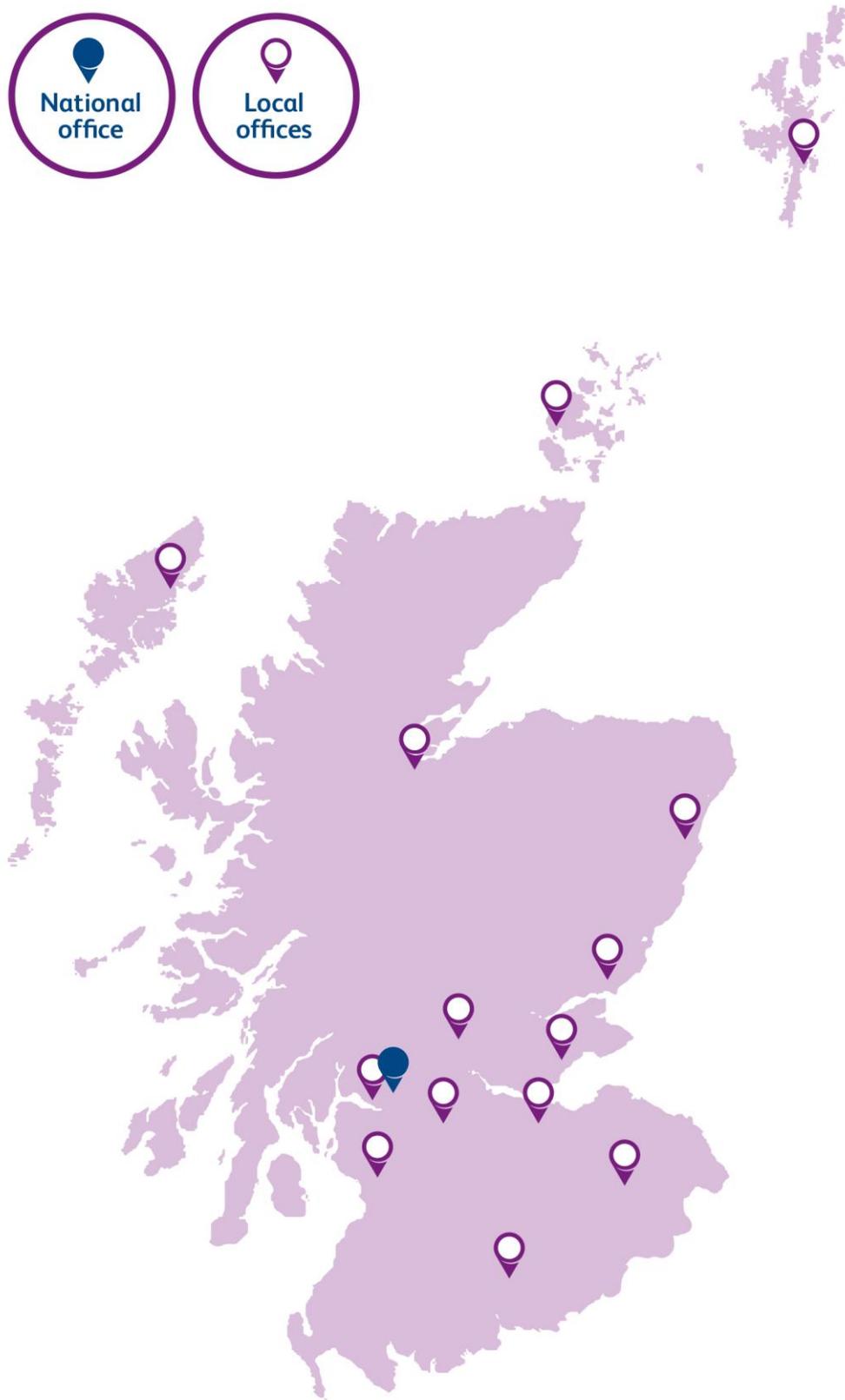
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Scottish Health Council National Office: Delta House | 50 West Nile Street | Glasgow | G1 2NP
Telephone: 0141 241 6308 **Email:** enquiries@scottishhealthcouncil.org

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