



### Gathering Views on Shared Decisionmaking and the use of 'Question Prompts'

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### Section 1 Background

- 1.1 Shared decision-making and enabling people to make informed decisions about their care based on what matters most to them is a priority across NHSScotland.
- 1.2 In July 2018 the Scottish Health Council carried out a gathering views exercise on behalf of the Chief Medical Officer on what Realistic Medicine meant to patients and members of the public<sup>1</sup>.
- 1.3 Furthermore, the Chief Medical Officer's Annual Report 2016-17, *Practising Realistic Medicine*<sup>2</sup>, acknowledged 'question prompts' as an effective and inexpensive intervention that could support patients to become more involved in medical consultations. 'Question prompts' are questions that are written down and given to patients in advance of their appointment for them to ask their healthcare professional.
- 1.4 In order to build on the previous work and support national policy development, the Scottish Health Council was asked by the Scottish Government to hold discussion groups and individual interviews with members of the public to ask how they felt about the use of 'question prompts'. We shared with participants some samples of 'question prompts' and asked them for their views. We also asked them what would encourage people to use the questions in consultations.

The objectives were to:

- explore views on examples of different kinds of 'question prompts'
- understand what would encourage people to use the questions in consultations
- explore what people thought about the use of questions in different settings and whether a consistent approach across Scotland was important, and
- understand what other aspects were important in supporting people to have conversations with healthcare professionals.

<sup>&</sup>lt;sup>1</sup> <u>http://scottishhealthcouncil.org/publications/gathering\_public\_views/realistic\_medicine.aspx</u>

<sup>&</sup>lt;sup>2</sup> <u>https://www.gov.scot/publications/practising-realistic-medicine/</u>

### Section 2 Approach

- 2.1 The Scottish Health Council's gathering public views methodology feeds public views into the heart of the development of policy and services. There are other examples of our gathering views work available on the Scottish Health Council's website<sup>3</sup>.
- 2.2 The approach we used was consistent with our normal gathering public views practice in that it is not undertaken as formal research nor as formal consultation. This engagement was intended to support the work undertaken by Scottish Government.
- 2.3 The Scottish Health Council regards gathering views via discussion with small groups of people as an effective way of obtaining feedback. Our main consideration is about the quality of engagement as opposed to the number of people involved.
- 2.4 The request for support for gathering public views included a need to hear from a diverse group of individuals in terms of age, gender and socioeconomic backgrounds and for group discussions to take place in a mix of urban and rural locations.

This gathering public views exercise was conducted in the following NHS Board areas:

- Ayrshire and Arran
- Fife
- Forth Valley
- Grampian
- Highland
- Lothian, and
- Western Isles.
- 2.5 A total of 78 participants took part in 11 discussion groups in October 2019 and we held separate interviews with three individuals. Discussion groups were arranged by Scottish Health Council local offices using links with local networks and communities and third sector organisations to attract participants.
- 2.6 Equalities monitoring information was gathered where it was appropriate to do so. Details can be provided upon request.

<sup>&</sup>lt;sup>3</sup> <u>http://scottishhealthcouncil.org/home.aspx</u>

- 2.7 Discussion sessions took place with a variety of groups and individuals including:
  - young people
  - people with long term conditions
  - young carers
  - people with experience of addictions and substance misuse
  - a cancer support group
  - people who had been through the justice system, and
  - other individuals including those with 'protected characteristics' of age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation.

The discussion groups took place in both urban and rural locations.

2.8 This report describes the views and feedback from participants.

### Section 3 Feedback

The following questions were asked of participants in the discussion sessions and individual interviews.

#### Asking questions in consultations and appointments

## 3.1 How comfortable do you feel asking questions in conversations with your healthcare professional about treatment options and alternatives?

Out of the 11 discussion groups, all participants in four of the groups felt quite comfortable about asking their healthcare professional about treatment options. Others however found it more difficult, particularly if they were a carer as they often did not feel fully included in the care of the patient.

Some individuals said they did not feel comfortable asking consultants questions about treatment options and found this difficult when compared, for example, to asking GPs or Practice nurses.

## 3.2 How comfortable do you feel asking questions in conversations with your healthcare professional about risks and benefits of treatment?

Many participants felt comfortable asking questions about risks and benefits of treatment although some felt that it would be useful for healthcare professionals to have more training to make it easier for patients and carers to ask questions.

Participants in one group said that it was easier to ask GPs about risks and benefits of treatment because of the trust they had in that professional and there was a degree of continuity of care when compared to a healthcare professional they could be meeting for the first time.

"You really have to be informed about risks and benefits and sometimes it would be good to be given time to reflect and ask further questions before committing to treatment."

Similar to feedback in section 3.1 above, carers said that they sometimes felt "left out" of the conversations between patients and healthcare professionals when it came to discussions about risks and benefits of treatment.

Participants said that they felt that in their experience pharmacists were much clearer when it came to discussing risks and benefits of treatment with patients when compared to other healthcare professionals.

## 3.3 How comfortable do you feel asking questions in conversations with your healthcare professional about what would happen if you did nothing and chose no treatment?

Many participants said they felt comfortable about asking what would happen if they did nothing and chose to have no treatment. They also felt that using a set of 'question prompts' in this scenario would be helpful. Some however felt that it would depend on the circumstance as it could be "frightening" for patients to receive bad news.

There was a view from some participants that "questioning professional advice would not be the best approach" as it could be perceived as "wasting the healthcare professional's time" if they chose not to take the advice or recommended treatment. A small number of participants felt that it would be less difficult to ask their GP about choosing to have no treatment, but one person said that "their GP did not like to be questioned".

Some participants said that in their experience it was sometimes difficult to ask healthcare professionals for help in identifying natural remedies or alternative therapies as a substitute for typical medications and drugs.

*"If people learn that certain treatments will not change their circumstances and choose not to proceed with them, it could save the NHS money on potentially unneeded prescriptions."* 

### 3.4 Do you find it easy to get the information that you want in conversations with doctors or healthcare professionals?

The question about how easy people find it to get the information they want in conversations with healthcare professionals prompted a mixed response. Some people found it relatively easy through routine conversations with their doctors or healthcare professionals whereas others less so. It was felt that having confidence and trust in the healthcare professional was key to enabling a positive discussion as well as the need for the patient to be prepared for the appointment in advance.

It was highlighted that if the individual patient was confident then that helped in getting what they needed from a conversation with their healthcare professional.

Some people felt that a lack of signposting to healthcare professionals made it challenging for patients to find the information they needed. Participants also said that they often found information "by chance", for example if someone they knew was aware of a particular patient support group, or if their key worker directed them to where they could obtain information.

There were suggestions that doctors may benefit from training in signposting patients to relevant groups and organisations that could provide additional support to patients.

There was some discussion about the use of the internet and how that could be used as a way of getting information, albeit that participants recognised that that could lead to patients receiving conflicting and even incorrect information. There was also a view that patients being "pre-armed" with information about a condition from the internet was not always "well received by GPs".

Some carers said they felt it was difficult to get the information solely through conversations with healthcare professionals. They said that sometimes they felt that they were not included in discussions and, in some cases, they were "not allowed" to be in the room during the consultation. Carers said that this could have a huge negative impact in cases when, for example, the carer was responsible for ensuring the patient received their medication – there was particular reference here to medication dosage and potential side effects.

Participants said that whilst they thought 'question prompts' could help to start a conversation with a healthcare professional, those professionals also needed to ensure that they listened to what was important to the patient (and act upon it).

### *"Even (their) diagnosis was hard to understand, I felt forgotten about."*

Time available at appointments was seen as an important issue for participants. Participants felt that if 'question prompts' were going to be used, the length of appointment times needed to be longer to accommodate the discussion. In some instances, patients or carers felt they currently could not ask questions primarily because there was not enough time at their appointment.

#### Questions about the use of 'question prompts' for patients

### 3.5 Do you know that it's your right to ask your doctor or healthcare professional questions about your health, treatment and care?

The majority of people who took part were aware that they had a right to ask healthcare professionals and doctors about their health, treatment and care. The remainder either had some awareness or were unsure (for example if they were in a caring role). There were some people who were not aware of their right to ask questions. 3.6 Do you think providing patients with 'question prompts', (questions that are written down and given to you in advance of your appointment for you to ask your health professional), is something that would be helpful in improving conversations between patients and healthcare professionals?

### Do you think that 'question prompts' will help you get the answers you need to make an informed choice about your treatment and care?

A small number of people did not think that 'question prompts' would be helpful. The reasons they gave were around a lack of confidence to ask questions or not feeling the need to use them because they already felt confident enough. The majority of participants said that 'question prompts' would be helpful especially in terms of:

- keeping the appointment and any discussions focused
- helping to start and improve conversations
- helping to remind patients about issues to discuss
- giving a purpose and clear reason for the appointment, and
- helping to prevent feelings of being rushed at the appointment.

Some participants thought 'question prompts' would be useful but it depended on what the questions were. They highlighted that there was a need to decide whether questions could be adapted for specific conditions, rather than for general use. It was also highlighted that a question on the prevention of ill health would be useful.

Some participants highlighted that previously they had been advised that they could only discuss three things in their appointment with their GP so trying to decide what to prioritise would be difficult. They said that the limitation on what they could discuss made them feel "unheard" and "rushed".

Some carers were unsure if 'question prompts' would be useful and remained of the view that it would still be difficult to feel and be more involved in the care of a patient with or without them.

It was felt that healthcare professionals within hospital settings (secondary care) were better at ensuring carers were included in discussions with patients around choices and general health issues. They felt that this differed with their experience of GPs and some carers said they had been asked to leave the room during the consultation. These participants felt that 'question prompts' would work better in acute care services as opposed to primary care.

Some people expressed reservations about using 'question prompts' if the responses were not going to be acted upon. It was highlighted how this could lead to a loss of trust and prevent people coming back with more questions around what they really needed to know and understand.

*"Remember that not everyone can read. Information that is only available in a written format can actually take power away from some of the most vulnerable patients, for example those with a low literacy level or those with a visual impairment."* 

Participants mentioned the importance of education and the need for both patients and healthcare professionals to be clear about why 'questions prompts' were being used and the benefits of using them. Participants also mentioned the limited time available at GP appointments.

#### Possible types of 'question prompts'

Participants were shown four different types and layouts of 'discussion prompt' questions (see Appendix) and were asked the following questions.

## 3.7 Do you think any of these 'question prompts' will help you make an informed choice about your treatment and care?

The majority of participants thought that the use of 'question prompts' would help patients make an informed choice about treatment and care. They also said it would make appointments more focused, give patients more control and add clarity to some of the discussions. One group described the questions as "fabulous".

Participants were of the view that individuals needed to take more responsibility for their own health and lifestyles with possibly the support of other healthcare professionals such as pharmacists etc. The groups shared their ideas about further 'question prompts' and suggested these could cover:

- diagnosis
- medication
- additional support after treatment
- side effects of treatment, and
- risks associated with any treatment.

Some participants felt that a standardised set of 'question prompts' would not work in all consultations and/or settings.

"Individual needs are not always the same and the same approach would not suit everyone."

# 3.8 From what you have seen, what sets of questions do you think work well or best? What do you like or dislike about different versions of these questions?

Participants were shown a set of four different styles of 'question prompts' (see Appendix). The feedback they shared was vast and varied and the finer detail of their comments, suggestions and recommendations has been shared with the Scottish Government. Below is a flavor of the types of suggestions participants made.

#### Set 1: Choosing Wisely's 5 Questions

In summary, participants said that they liked the wording of this set of 'question prompts' although the 'Choosing Wisely's 5 Questions' was the least favored by participants in one group. Participants advocated the use of diagrams to highlight information and recommended improvements to make the document more colourful and eye-catching. Some people were not keen on including questions about side effects and others felt that some questions could be regarded as "questioning the judgment of the clinician" because of the way the question was written.

Other feedback included the need for the text to be larger to ensure that it was accessible.

#### Set 2: BRAN - Benefits, Risks, Alternatives, Nothing

In summary, participants liked the simple layout of this set of 'question prompts' but suggested that it needed to be more colourful and include appealing graphics. Some felt that it was "too wordy" whereas others felt that it was a user friendly layout. Whilst some participants felt it was easy to follow and accessible, others felt it was not "eye-catching" enough and, therefore, seemed "less professional". One group said this example was their preferred set of 'question prompts'.

#### Set 3: It's Okay to Ask

In summary, participants said they felt this set of 'question prompts' was eyecatching and they particularly liked the "pros and cons" question. They also liked the question about "helping my own health" but felt that this set might prompt more questions once asked. This was the least favoured set within one group.

### Set 4: 5 Questions to ask at your appointment before you get any test, treatment or medicine

In summary, comments about this example were varied. Participants felt that the question relating to risks about treatments was an appropriate one and that overall this set of 'question prompts' seemed user friendly. In terms of layout, they felt it was less professional looking than some of the other examples and needed to be more eye-catching. Participants felt that a question about whether treatment was necessary was superfluous but overall felt the questions were relevant for all conditions.

There were other comments about the design (including a suggestion to change the shape of the text box so that more information could be included). One participant felt that the question about "how to improve my condition or health" could be misleading, particularly for anyone with a long term condition.

Two groups preferred this set of 'question prompts'.

#### 3.9 Further comments

Many participants expressed concern about the time that would be needed to go through any set of questions and whether they would have sufficient time during an appointment. It was highlighted that it would also be helpful to provide 'question prompts' for school children, the visually impaired, people whose first language is not English and individuals with learning difficulties. Some thought that older people may prefer simpler layouts to make them more accessible.

Some of the 'question prompts' which were considered contained an option for people to indicate a nil response. Rather than describing that as an option of "nothing", participants suggested an alternative, for example "no action" or "no treatment".

Some people suggested that providing a more pictorial visual set of questions would be useful and others felt that if the "BRAN poster" example was changed to be more eye-catching, for example in the style of a coloured ladder, it would make it easier to remember the questions.

### 3.10 Do you think the same set of questions should be used across Scotland, no matter where you live?

Everyone that answered this question thought that the same set of questions should be used across Scotland but there should be an option for local flexibility if needed. There was a suggestion that 'question prompts' could be developed as "recommended guidance" as there needed to be recognition that some patients might not want to ask the same questions in all settings.

"The basis of the questions should be the same throughout Scotland but with some consideration given to a local context."

Questions about encouraging the use of 'question prompts'

3.11 What do you think are the best ways to promote the use of 'question prompts' (for example, leaflets in GP surgeries, or on appointment letters, via social media, TV or radio campaigns or newspaper adverts etc?)

Participants shared a variety of suggestions of how the use of 'question prompts' could be promoted. These included:

- large posters and leaflets displayed in waiting areas and consulting rooms
- apps on mobile phones and text messages
- credit card size cards with prompts for individuals to keep
- screens and televisions in waiting rooms with ticker tape messages
- reminders from staff that it is "okay to ask"
- newspaper advertising and social media campaigns (potentially with celebrity endorsement)
- reminders on appointment letters
- information at libraries, chemists and community centres, and
- promotion in schools, cinemas and advertising on buses.

### 3.12 What would be most likely to encourage you to use these types of questions?

Participants said that the most likely way to encourage patients to use 'question prompts' would be:

- if the healthcare professional invited and encouraged patients to use them
- if there was sufficient time during an appointment
- where there was more than one issue to discuss with a healthcare professional
- seeing a campaign strapline on an appointment card
- if there were prompts for use with receptionists
- if it was beneficial to their own health for example, looking after oneself, and
- if the questions were clear as well as the benefits of using them.

### 3.13 Do you think we should promote the use of 'question prompts' in different ways?

All participants who answered this question agreed that the use of 'question prompts' should be promoted and that different formats and languages should be used.

### 3.14 What do you think would be the most helpful message to encourage people to ask questions?

Participants had a range of views about how to encourage people to ask questions including:

- a reminder from the receptionist when checking in to an appointment
- by eliminating medical jargon and keeping it simple with plain language
- making the 'question prompts' accessible to patients
- if a "snappy header" was used such as "don't leave in doubt; ask these questions"
- buy-in and support from healthcare professionals
- an "It's okay to ask" campaign so that patients feel more confident in asking questions, and
- patient education in a variety of settings such as community centres, schools etc.

#### "We are all human – you don't get answers if you never ask!"

#### Questions about making it easy for patients to ask questions

## 3.15 How could doctors and other healthcare professionals make is easier for you to ask questions about your treatment and care?

Participants felt that if healthcare professionals highlighted the 'question prompts' during their consultation it would be helpful and encourage them to use them. In addition, it would be useful if the patient or carer was asked at the end of the consultation if they had anything more to ask.

There was also a suggestion that this could include a conversation about potential alternative treatments. Participants also said that it would be useful to ask whether everything had been covered during the appointment and that would then give the patient, carer and the healthcare professional time to reflect before leaving. Participants felt that it was important for healthcare professionals to show they had time to answer questions without making the patient feel they were "being a burden".

Other suggestions from participants on how to encourage people to ask questions included:

- building relationships with the healthcare professional
- prominently displaying large posters which the GP could refer to after a consultation
- having recognisable branding that is instantly noticeable, including to people whose first language is not English
- using the correct tone of voice and language to encourage people to ask questions, and
- introducing an electronic log-in system with 'question prompts' included.

## 3.16 Would using 'question prompts' be the same in all settings, for example in a hospital and in a GP practice?

Many participants thought that having a consistent approach across Scotland for 'question prompts' would be beneficial and avoid confusion. Some participants were unsure if the use of 'question prompts' would work with all consultants, however,

they felt that the questions could work in a hospital setting. They highlighted that their concern was more to do with individual consultants rather than the content of the questions and suggested that training may be required for some.

One group suggested that any campaign about the use of 'question prompts' should be about encouraging people to take ownership of their own health by increasing confidence to ask their own questions rather than having a specific set of predetermined questions.

Another suggestion was to use a strapline and main message for 'question prompts' across the whole of Scotland adding different examples and scenarios for specific settings. However, it was also felt that it was important not to over complicate things. Some people suggested piloting different approaches in various settings as they felt that could illustrate what worked best. One participant thought this should be done on a case-by-case basis – for example having a different approach between primary and secondary care as there may be different risks or "life threatening decisions" to be made in an acute setting.

## 3.17 Is there anything else that you would like to say about 'question prompts' or improving conversations between patients and healthcare professionals?

The common theme from participants was around limited time at consultations and appointments. In particular, people were concerned that healthcare professionals could be too busy to use 'question prompts' and so they were not sure how well it would be received by them.

Communication, terminology, trust and relationships were seen as key to having open discussions. Participants also felt there needed to be more access to an interpretation service for those whose first language is not English.

Some participants felt that GPs would not have an in-depth knowledge about their specific condition when compared to a consultant and this was felt to be limiting for the shared decision-making approach generally. Participants also said that being mindful of patients' own knowledge of their health was important as well as the need for people to take control of managing it. They added that this included being prepared for the consultation.

It was felt that the formality of health environments and settings could be a barrier to good communication – participants said that wearing name badges and using first names could be one way to help break that down. They also felt that further consideration of the questions with the flexibility to have more added such as 'what does this mean for me?' and 'where can I get more information?' would be useful for some.

Some participants felt it would be helpful to pilot the questions and have a follow-up review to see if they are working in practice. It was suggested that these could be piloted through local groups such as Patient Participation Groups.

#### Question about preparing for a consultation

In our previous gathering public views exercise about shared decision-making, the Scottish Health Council found that 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. We wanted to explore this further with participants and asked them about preparing for a consultation.

## 3.18 Are there any other ways in which you think people can be supported to prepare for consultations with their doctor or healthcare professional so they get the most out of the conversation?

Some participants felt that this depended on what the consultation was for. They said that communication was key throughout the discussion groups and the need to ensure that GPs and doctors were accommodating to other opinions and give the individual a chance to have their say during the appointment/consultation was also important.

Some felt that having 'question prompts' would not help to address all healthcare concerns, ranging from the initial making an appointment through to collecting prescriptions. It was noted that many individuals will look up information about their condition on the internet and so including links to appropriate websites in appointment letters could be beneficial. They said that conducting research and being better informed about a condition meant that a person was more likely to know what questions they wanted to ask.

It was also felt that having visual prompts, extended appointment times and continuity of care would allow for questions and meaningful discussions.

Many participants referred to the importance of being able to take someone with them into an appointment. Carers said they tended to make a list of questions prior to appointments so that they are able to tick each one off once discussed and ensure that nothing was missed. They felt that it was important to have this option promoted to patients and that could be done when the appointment was sent out. If 'question prompts' were introduced then reference could be made to that option in the appointment letter.

One group suggested that having a campaign launch at a General Practice, as well as educational events and sessions for patients, would help to promote the use of 'question prompts'. Others suggested using leaflets and support groups to "spread the word".

### 3.19 Do you think doctors and healthcare professionals should ask people whether they need help from their family or someone independent to help them with decisions about their treatment and care?

All participants agreed that people should be asked if they needed help from their family or someone independent but some questioned whether or not this would be welcomed by healthcare professionals and whether many patients were aware of the option of having someone independent to help them. Participants said that they were aware of instances when information was not easily processed by patients and so having someone to digest information, take notes and support them would be "incredibly useful". They also felt that patients should be asked by a healthcare professional if having someone independent to help them with decisions was needed, irrespective of what type of appointment it was.

### **Section 4 Summary**

In summary, the majority of participants supported the use of 'question prompts' and were able to identify and understand the benefits to both patients and healthcare professionals.

During our conversations with participants, the following five key themes emerged.

- The lack of time available for 'question prompts' to be used and the need to extend appointment times if they were to be successful in practice.
- The need for a comprehensive approach to ensure that all healthcare professionals and support staff, including consultants, GPs, pharmacists and reception staff were included in the use of 'question prompts'.
- The need for 'question prompts' (if introduced) to be widely publicised and promoted to ensure everyone is aware of their right to ask and what healthcare professionals can expect to be asked.
- Effective and clear communication is required to break down barriers and ensure there is a meaningful discussion between patients and healthcare professionals.
- The approach of including carers and supporters in conversations with healthcare professionals should be supported and promoted widely.

### **Section 5 Next Steps and Acknowledgements**

- 5.1 The Scottish Health Council would like to thank everyone who took part and shared their views about the use of 'question prompts' and their suggestions for improvement.
- 5.2 All feedback received has been shared with the Scottish Government and the information gathered through this work will be used alongside other evidence collected on shared decision-making to inform a workshop for policy and clinical leads on next steps in promoting the use of 'question prompts'. This will include decisions about potential national branding and marketing.
- 5.3 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 Samples of Question Prompts**

#### **Choosing Wisely's 5 Questions**

To help ensure you have all the information you need to make the right decisions about your care, please ask your healthcare professional:

- Is this test, treatment or procedure really needed?
- What are the potential benefits and risks?
- What are the possible side effects?
- Are there simpler, safer or alternative treatment options?
- What would happen if I did nothing?

#### BRAN (short for Benefits, Risks, Alternatives, Nothing)

Four questions to ask my clinician or nurse to make better decisions together

- 1. What are the Benefits?
- 2. What are the Risks?
- 3. What are the Alternatives?
- 4. What if I do Nothing ?

### It's Okay to Ask



### <u>5 Questions to ask at your appointment before you get any test, treatment or</u> <u>medicine</u>



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- 電子郵件
- 大版面印刷
- 語音磁帶或 cd
- 盲文,以及
- 其他語言版本

آپ ہماری ویب سائٹ پر اس دستاویز کو پڑھ اور ڈاؤن لوڈ کرسکتے ہیں۔ ہم یہ معلومات درج ذیل کے ذریعہ بھی فراہم کرسکتے ہیں:

- بذریعہ ای میل
- چھاپے کے بڑے حروف میں
  آڈیو ٹیپ یا سی ڈی کی شکل میں
  بریل میں ، اور
  دیگر زبانوں میں



The Scottish Health Council has a national office in Glasgow and a local office in each NHS Board area. To find details of your nearest local office, visit our website at: www.scottishhealthcouncil.org/contact/local\_offices.aspx

www.scottishhealthcouncil.org

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