



Our Voice Citizens' Jury on Shared Decision-making

March 2019



Produced in partnership with:



© Ourvoice 2019
Published March 2019

This document is licensed under the Creative Commons Attribution-Noncommercial-NoDerivatives 4.0 International Licence. This allows for the copy and redistribution of this document as long as Healthcare Improvement Scotland is fully acknowledged and given credit. The material must not be remixed, transformed or built upon in any way. To view a copy of this licence, visit <https://creativecommons.org/licenses/by-nc-nd/4.0/>

www.scottishhealthcouncil.org/our_voice/our_voice.aspx

Contents

Introduction	4
What is a Citizens' Jury?	5
The sessions	17
Recommendations	27
Citizens' Jury Launch Event	32
Appendix 1: commentator sessions	34
Appendix 2: session plans	36
Appendix 3 – Notes from themed discussions	39

Introduction

In the autumn of 2018 a diverse group of Scottish citizens gathered over three days to make recommendations on shared decision-making in health and social care.

The 24 citizens shared ideas, opinions and experiences and questioned expert commentators before attempting to reach some consensus.

This report documents the process followed and lists, in the participants' own words, their recommendations.



What is a Citizens' Jury?

Many institutions across the world have started to recognise the importance of involving members of the public in helping make important and difficult decisions.

A Citizens' Jury is the bringing together of a diverse group of between 12 and 25 members of the public who are usually randomly chosen. Their task is to work through an issue, share ideas and perspectives, explore options and eventually come up with a set of recommendations.

They are helped by experienced 'facilitators' who help make sure everyone has a fair say and that the task is achieved. As part of this deliberative process, there is also input from external people who can offer particular insight or expertise. These people are known as commentators or expert witnesses.

Well-designed Citizens' Juries create insightful results that would not be achieved through a consultation, focus group or survey. In addition, the process nearly always produces a group of enthusiastic motivated residents interested in taking action.

First used in the 1970s by the Jefferson Centre in the US, Citizens' Juries were introduced into the UK in the mid-1990s but are still rare within Scotland. Their use is, however, widespread across the world, on a vast range of topics ranging from the use of genetically modified crops in Mali (2006) to Nuclear Waste Storage in South Australia (2016).

Deliberation

"Deliberation includes exchanges between two or more people around a common topic with back and forth reactions to each other's views, puzzling over an issue to work something out collectively, the sharing of reactions, trying to understand the position of others, a willingness to be persuaded by another's position. There is the possibility of disagreement, conflict and argument and discussion of that disagreement. Ideally all this discussion should lead to a consensual resolution or of conclusion to the question being explored."

– Davies et al 2006



Why a Citizens' Jury?

The Chief Medical Officer's 2014-15 annual report, 'Realistic Medicine'¹, called for changes in the way care is delivered in Scotland. The Chief Medical Officer has challenged healthcare professionals to consider how we can build a more personalised approach to care, reduce harm and waste, manage risk better, reduce unwarranted variation in health, treatments and outcomes and find innovative ways to improve the way healthcare is delivered in Scotland.

An important aim of the Realistic Medicine agenda is to foster and promote shared decision-making. That is, where decisions about a person's care or treatment are made jointly and in partnership with healthcare professionals and the individual receiving care (and if required, with others supporting their care, such as their families, guardians or advocates).

The follow-up annual report (2015-16), Realising Realistic Medicine², set out the Scottish Government's plans to hold a Citizens' Jury to help implement the vision.

Subsequently, the Scottish Health Council³ was asked to manage and evaluate⁴ a Citizens' Jury on the topic of Realistic Medicine. Plans for the Citizens' Jury became one element of the Our Voice programme, which was developed to support people and their families to engage at every level in health and social care⁵.



Realising Realistic Medicine

"Over the course of 2017, with support from the Scottish Health Council and The ALLIANCE, we look forward to establishing what Realistic Medicine means to people we care for and support and the wider public. We must gain a true understanding of what the concepts described in Realistic Medicine mean for those accessing health and care services, in order that we can truly co-produce a realistic approach to health and social care. A number of methods will be used to find out how best to achieve this, including focus groups, the Citizen's Jury and Citizen's panel."

– Realising Realistic Medicine: Chief Medical Officer's Annual Report 2015-16

1 Chief Medical Officer's 2014-15 annual report, Realistic Medicine

2 Realising Realistic Medicine: Chief Medical Officer for Scotland annual report 2015-2016

3 <http://scottishhealthcouncil.org/home.aspx>

4 The Scottish Health Council's evaluation of the Citizens' Jury will be published in 2019 and will be available on the Scottish Health Council website.

5 http://scottishhealthcouncil.org/our_voice/our_voice.aspx

In 2017 Our Voice commissioned the social enterprise Shared Future CIC to conduct an initial literature review⁶ and options appraisal to help inform final decisions on the jury design.

Drawing on advice from the Our Voice Programme Board, the options appraisal, stakeholder engagement and the literature review, the decision was made for the focus of the Citizens' Jury to be the shared decision-making element of Realistic Medicine.



Citizens' Jury literature review

This specially commissioned document takes a snapshot of relevant literature to discuss the features of citizens' juries, their use (both in Scotland, England and internationally) and the Scottish context.

The review considers questions around the design elements of the process and offers a critique of citizens' juries and other mini publics in particular the ability of citizens' juries to be inclusive and to impact upon decision-making processes.

The work of the Citizens' Jury was designed to complement questions about shared decision-making which had already been put to the Our Voice Citizens' Panel⁷, made up of around 1,200 people from all walks of life drawn from across Scotland. The panel is broadly representative of the population as a whole. This consultation was conducted via a survey and did not involve deliberative engagement.

After a competitive tendering process in the summer of 2018 Shared Future⁸ was commissioned to design and facilitate the Jury on the topic of shared decision-making.

This was the first Citizens' Jury commissioned by the Scottish Government to consider a healthcare topic. Its intention was to:

- offer further insight into how relationships between health and social care professionals and service users might be strengthened i.e. (shared decision-making), and
- assess the role of Citizens' Juries as an innovative approach to citizen involvement in the policy-making process.

⁶ Citizens Jury Literature Review: Shared Future and Our Voice (2017)

⁷ The second report of the Our Voice Citizens' Panel in 2017 focused on members' views on shared decision-making with health and social care professionals

⁸ The Shared Future team have designed and managed over 30 Citizens' Jury processes over the last 10 years

The Citizens' Jury commissioners decided that the Citizens' Jury pilot should take place over a total of three days. Shared Future recommended that these three days should be split with a two-week gap between each session. This would mean a less intense time commitment for participants and crucially also provide an opportunity to reflect between sessions.

The question

Clearly the setting of the right question for Jury members to consider is central to the success of the Citizens' Jury process. However, this is not easy. Too broad a question and the group may be unable to move beyond broad recommendations. Too narrow a focus and the Jury members may feel they do not have the permission to explore some of the wider context influencing the issue under consideration.

The Scottish Government recognised it is essential that the question put to the Jury is meaningful to members of the public and that it is sufficiently substantial to stimulate meaningful deliberation. Having a well-focused question would enable the Jury to use its time effectively to address the question (rather than discussing the definitions and parameters of the question).

In the summer of 2017, during the initial options appraisal, a series of stakeholder engagement workshops facilitated by Shared Future and supported by the Our Voice team explored potential questions. From this process the following shortlist of questions was generated:

Question 1: What should shared (or joint) decision-making look like between the individual and the people involved in their care, and what things are needed to allow this to happen?

Question 2: What would it take to genuinely include 'me' in 'shared decisions' about my health and social care?
What communication approaches are needed?

Question 3: What does shared decision-making with a health or social care professional mean to me and what do I need for it to be possible in every interaction?



“Time and time again, evidence from citizens' juries demonstrates that, where there is not a clearly defined, narrow and focused agenda there will be poor quality deliberation.”

– Elstub, S. (2014) 'Mini-publics: issues and cases' IN Deliberative Democracy: Issues and cases. Edinburgh University Press

After lengthy discussion at the project's first Oversight Panel the following question was agreed:

The Citizens' Jury question

When decisions about a person's care or treatment are made jointly between health or social care professionals and the individual, or others supporting their care, it's known as shared decision-making. The question the Citizens' Jury will attempt to answer is:

'What should shared decision-making look like and what needs to be done for this to happen?'

Oversight Panel

In keeping with good practice in the design of deliberative processes⁹ the Citizens' Jury was supported by an Oversight Panel, which met on a number of occasions parallel to the Jury process. The role of the Panel was to:

- ensure that the process is fair and rigorous
- agree on the question to be posed to the Citizens' Jury
- suggest topics to be considered by citizens in the process
- identify commentators/witnesses best able to present on these topics
- monitor the process of citizen selection
- comment and offer guidance on the draft evaluation framework, and
- advise on the dissemination of the Jury's findings.

At an early stage it was identified that the Oversight Panel should be made up of a diverse range of stakeholders – both to ensure the legitimacy of the process and, where appropriate, to support implementation of the Jury's recommendations.

During some of the stakeholder workshops held in 2017 participants talked of the importance of an oversight function and in particular the need for a very carefully chosen "neutral Chair" who would be seen as impartial to the issue under consideration. The Scottish Government proposed Erica Reid, Associate Director of Nursing and Allied Health Professionals, NHS Borders, to lead the Oversight Panel of this pilot Citizens' Jury.

⁹ Two thirds of the health-related citizens' juries examined by Street et al (2014) established a steering committee or advisory group made up of key stakeholders i.e. policymakers, experts in the field under consideration, advocacy group representatives, clinical practitioners, deliberative methodologies and patients.

The Oversight Panel met on four occasions in Edinburgh, including at the start of the process, between Jury sessions and after the final session.

Working alongside the Oversight Panel was a small Implementation Group whose function was to support the work of the Oversight Panel and to check logistics. The membership of this group included Helen Mackie (National Clinical Advisor, Realistic Medicine, Consultant Gastroenterologist, NHS Lanarkshire), Gary McGrow (Social Researcher, Scottish Health Council), Erica Reid (Chair of the Oversight Panel and Associate Director of Nursing and Allied Health Professionals, NHS Borders), and Joanna Swanson (Person-Centred and Quality Team, Directorate for Healthcare Quality and Improvement, the Scottish Government).

The Implementation Group and some members of the Oversight Panel attended the Jury meetings as observers to the process. They were:

Keith Chapman	ALLIANCE Member
Susan Clerk	ALLIANCE Member
Rachel Creaney	Scottish Government (Intern)
Gary McGrow	Scottish Health Council
Erica Reid	NHS Borders
Alix Rosenberg	Scottish Government
Joanna Swanson	Scottish Government
Professor Andrew Thomson	University of Edinburgh

Oversight Panel membership

Erica Reid (Chair)	Associate Director of Nursing and Allied Health Professionals, NHS Borders, Chief Nurse Health and Social Care Partnership.
Helen Mackie	National Clinical Advisor, Realistic Medicine, Consultant Gastroenterologist, NHS Lanarkshire
Professor Andrew Thompson	Chair of Public Policy and Citizenship, Politics and International Relations, School of Social and Political Science, University of Edinburgh
Dr Graham Kramer	GP, Royal College of General Practitioners Scotland Executive Officer (Patients and Public), former Health Literacy lead for Scotland (RCGP nomination)
Carol Clugston	Royal College of Physicians of Edinburgh Lay Advisory Committee
Dr Margaret McCartney	GP and journalist
Irene Oldfather	The ALLIANCE, Director of Strategic Partnerships
Rod Finan	Professional Social Work Adviser
Sarah Gledhill	Workforce Development and Regulation Team Leader (Chief Social Work Adviser nomination)
Karen Stewart	Healthcare Science Officer (Chief Nursing Officer nomination)
Keith Chapman	Service-user representative on the Midlothian Integration Joint Board
Suzanne Clark	Member of the East Renfrewshire Our Voice Group (Health and Social Care Alliance Scotland nominations of people with lived experience of using services)
Peter Bryant or Jez Hall	Shared Future, attended each Oversight Panel meeting in an advisory capacity



Members of the Jury

One of the defining features of the Citizens' Jury process is the participant selection. Many see the use of random selection as one of the Citizens' Jury's major strengths. In theory this approach avoids problems of self-selection by those with strongly defined opinions or a vested interest.

The reality is that most Citizens' Jury-style processes use a process of 'near random selection'. Citizens' Juries typically use a form of stratified sampling whereby the population is divided into a number of separate social groups. A random sample is then drawn from each group, with the aim of achieving as close to a representative sample as possible.

The recruitment of a sample of the general population was subcontracted to Research Resource who manage the Scottish Health Council's Citizens' Panel. Recruitment of the Jury members was started via a letter to a random sample of residents drawn from the electoral register. 3000 letters were sent out on the Chief Medical Officer's letterhead. Participants were encouraged to respond either by a pre-paid envelope, a web link or by phone. This targeted people enrolled on the electoral register within a 45-minute travel time from Perth. This included people living within five Health and Social Care Partnership areas of Perth and Kinross, Dundee, Angus, Fife and Clackmannanshire as well as three NHS Board areas (Tayside, Fife and Forth Valley).

Approximately 10% of those mailed responded, from which the final Jury members were selected by a stratified random sampling.

The stratified sampling profile was agreed by the Oversight Panel and aimed to ensure there was representation that reflected the general population across age, gender, ethnicity, geography (urban/rural) and those identifying as having a long-term health condition.

Recruitment profile	Original proposed profile	Actual profile of those recruited
Age		
16 to 25	6	5
26 to 44	6	6
45 to 64	6	7
65 and over	7	8
Gender		
Female	13	12
Male	12	14
Scottish Index of Multiple Deprivation		
1 (most deprived)	6	8
2	6	5
3	5	5
4	4	5
5	4	3
Urban / Rural		
Urban	20	20
Rural	5	6
Disability / long term health condition		
Yes	10	10
No	15	16
Ethnicity		
Ethnic Minority	2-4	3
White British	23-21	23

Shared Future advised the Oversight Panel that achieving representation within a small group is not easy and can highlight rather than reduce issues of marginalisation. To be the only person in a group with some unique characteristic can limit their participation.

For example, approximately 4% of the national population of Scotland lies in the minority ethnic category. For the Jury this would represent a single person. The Oversight Panel decided instead to aim for a recruitment target of at least two or three Jury members from this demographic.

In another example of over-representation of a minority, the Scottish Index of Multiple Deprivation (SIMD) was used as a proxy for health literacy¹⁰. The participant profile aimed to ensure there was representation across all five quintiles of the Scottish Index of Multiple Deprivation. However, the Oversight Panel decided it was important to skew slightly towards those from more deprived areas (SIMD 1-2).

This desire to ensure that seldom heard voices were sufficiently present in the Jury led to the organisers working on a recruitment target of 26, with the expectation that overall Jury numbers would drop either prior to or after the process started.

Location

Perth was selected as the venue for the Jury due to its relative proximity to a variety of urban and rural communities i.e. access to all six classes of the Scottish Government's urban/rural classification system.¹¹

Incentives

It is common practice in the UK to offer participants an incentive to take part in deliberative processes¹². Incentives are important to recognise the time commitment of attendees and to encourage those who may otherwise face, or feel they face, barriers to attending, thereby attracting frequently unheard voices.

The oversight panel decided upon a payment of £100 for attendance at each session. These payments were made at the final session. All participants were also offered payments to cover travel costs or essential support needs, such as paying for child or other caring responsibilities.

It is important to recognise that typically in Citizens' Jury processes many are encouraged to take part for reasons other than simply the financial incentive. Some participants will be driven by the desire to 'make a difference' and to feel that they are personally influencing the policy-making process.

¹⁰ The Scottish Government definition (2018) of health literacy 'is about people having the knowledge, skills, understanding and confidence to use health information, to be active partners in their care, and to navigate health and social care systems'.

¹¹ The Scottish Government's urban/rural classification system uses two main criteria: population and accessibility (based on drive time analysis to an urban area). The six-fold system recognises six different classes namely; large urban areas, other urban areas, accessible small towns, remote small towns, accessible rural areas and remote rural areas.

¹² There is a large variation in the amount paid as financial incentives e.g. Shared Future Citizens' Juries typically pay £20 vouchers for each 2.5 hour session attended, meaning participants over a ten session process can earn £200 (e.g. Central Blackpool Health and Wellbeing Inquiry 2017). Following advice from Ipsos MORI, who were commissioned to recruit participants for the Citizens' Juries on onshore windfarms in Scotland (2015), participants were paid £70 for Day 1 and £100 for Day 2. The participants of the Forest of Dean Citizens' Jury tasked with recommending a location for a new community hospital, were paid £100 per day.

In response to this desire, the Scottish Government agreed to make a clear commitment to respond to the Jury's recommendations within a certain timeframe and that the Chief Medical Officer should offer a personal thanks and commitment to all who took part. This was done through the recording of a video message shown at the beginning of the first session of the Jury.

Commitment

The Scottish Government has committed to carefully consider each of the Jury's recommendations and reply to them all, either with a commitment to action or an explanation as to why that recommendation cannot be taken

Ensuring Good Attendance

Research Resource received 269 applications and 26 people were invited to the first session.

All applicants that were offered a place on the Jury received a letter. Upon confirmation that they had a place they then received a phone call from one of the facilitators.

The aim of this call was to start to establish a facilitator/participant relationship, explain in more detail the process, respond to any concerns and to answer any questions.

Twenty-six people were invited to the first session with an expectation that some would fail to attend.

Twenty-four people came to the first session and attended the subsequent two sessions. Consistent attendance over a number of sessions is very rare and testament to the commitment of the Jury participants.

The table on the following page is a summary of the profile of those in attendance.

Recruitment profile	Attendance at session 1	Actual profile of those recruited
Age		
16 to 25	4	5
26 to 44	5	6
45 to 64	7	7
65 and over	8	8
Gender		
Female	12	12
Male	12	14
Scottish Index of Multiple Deprivation		
1	6	8
2	5	5
3	5	5
4	4	5
5	4	3
Urban / Rural		
Urban	17	20
Rural	7	6
Disability / long term health condition		
Yes	9	10
No	15	16
Ethnicity		
Ethnic Minority	3	3
White British	21	23
Total	24	26

The sessions

The Citizens' Jury took place on three Saturdays in the autumn of 2018 at the Station Hotel in Perth. The sessions took place on Saturday 27 October, Saturday 10 November and Saturday 24 November). Each session lasted from 10am until 4:45pm and was led by Peter Bryant and Jez Hall, two of Shared Future's experienced facilitators.

The following is a description of the Jury process. Facilitators chose a range of tools and approaches that would help Jury members to work effectively together, deliberate on the question and ultimately write a set of recommendations. In the early sessions there was an emphasis on helping people to feel relaxed and to start to develop relationships with each other (e.g. using ice breakers and swapping participants around in small groups). As confidence within the group grew the facilitators used techniques such as rapid one-to-one conversations, to enable participants to recognise the huge wealth of knowledge and experience within the group itself. Throughout the process participants were given the opportunity to express themselves in the plenary (big group), in small groups and in pairs. Finally, towards the end of the process activities such as 'Where do I stand?' attempted to build consensus before the final vote.

Session 1

The first session was of critical importance.

For those who, like many of us, are anxious in new situations, the first session should answer a range of questions; for example; why is this process being organised? Will I feel welcomed and valued? What will the other people there be like? Will this process make any difference? Who are the organisers?

On day one facilitators attempt to answer these concerns and create a relaxed and informal atmosphere where people will feel comfortable in listening and contributing to discussions within the group. Transparency is also key with a full explanation of why the process has been commissioned.

An initial introduction from facilitators helped participants to better understand the process that lay ahead and gain an idea of the facilitators' intended ways of working (i.e. a relaxed approach, the option to speak as little as desired, the use of small groups, the importance of clear simple language, anonymity and confidentiality).

This was followed by an introduction and question and answer session with Erica Reid, the Chair of the Citizens' Jury Oversight Panel, who explained the origins of the project and the Scottish Government's commitment to responding to the group's recommendations.

This information was re-emphasised by a specially-commissioned video message from the Chief Medical Officer, Catherine Calderwood¹³.

Central to the success of all deliberative processes is the ability of a diverse group of people to start to feel relaxed and comfortable in each other's company. Only once this is achieved can organisers hope that open and honest deliberation will take place. With this in mind, early in day one facilitators used two 'getting to know you' activities: People Bingo and the construction of a large human map.

What does shared decision-making mean for you? What does it/could it look like?

Participants were then asked to form small groups and to first think about what shared decision-making looks like and to try to draw it on the flipchart (or write lots of words that they thought were central to or important when attempting shared decision-making).

Secondly, if they felt comfortable to do so, to start sharing any good or bad experiences that they, friends or family members may have had of shared decision-making.

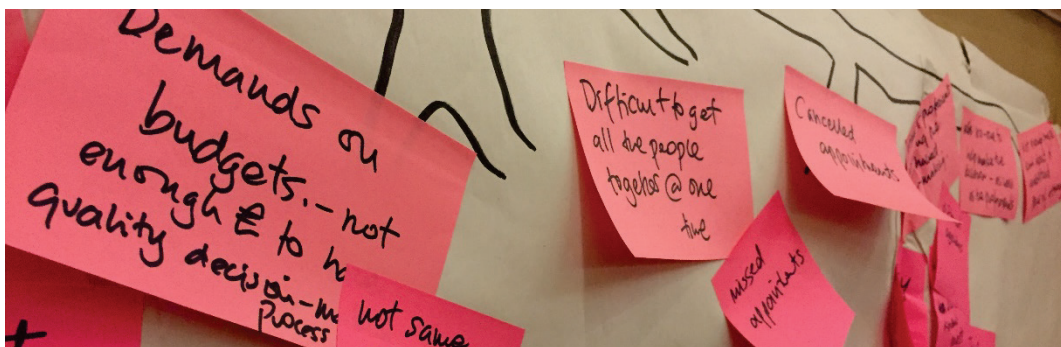
A large group feedback session enabled facilitators to encourage and validate those who took the risk of sharing personal experiences with the group.

Digging deeper: problem trees

All participants divided into two groups with each group using the problem tree methodology to analyse some of the root causes of the posed problem: '*it is difficult to achieve real shared decision-making*'.

Jury members attempted to identify the root causes of the problem (written on post-it notes at the base of the tree) and the effects (on leaves at the top of the tree) of what happens if real shared decision-making is achieved.

Once again the learning from this activity was shared in a large group feedback. After a short break, participants took part in their first commentator slot.



¹³ the Chief Medical Officer's video link is: <https://youtu.be/g0e69fwt9fo>

Commentators



Another key feature in most Citizens' Jury practice is the inclusion of the witnesses or commentators, who offer participants their own perspectives on the issue before being cross-examined by the Jury. It is through this questioning process that the Citizens' Jury model draws most heavily from the features of the legalistic jury.

It is part of the role of the Oversight Panel to both suggest topics to be considered by citizens and to identify commentators best able to present on these topics. However, the Citizens' Jury is about putting members of the public at the centre of decision-making. Such processes work most effectively when citizens themselves are able to have some power to decide what they feel needs to be talked about, rather than being rigidly constrained by the topic boundaries set by the commissioning body.

As a result, at the end of the first session, the facilitators invited Jury members to discuss which issues they felt need to be explored in sessions 2 and 3 in more depth in order to answer the overarching question. The Oversight Panel then decided from a long list of potential commentators which were best placed to respond to the requests of the Jury.

The commentators that presented to the Citizens' Jury are listed below.

Commentators		
Session 1		
1	Helen Mackie	National Clinical Advisor, Realistic Medicine, Consultant Gastroenterologist, NHS Lanarkshire
2	Dr Julie McElroy	Campaigner on diversity and disabilities
3	Andrew Cassidy	Care Opinion
Session 2		
4	Dr Graham Kramer	GP
5	Tommy Whitelaw	UK Project Lead, Dementia Carer Voices, Health and Social Care Alliance Scotland
6	Pauline McFadden	Carer
7	Shaben Begum	Director, Scottish Independent Advocacy Alliance
8	Andrew Murray	Medical Director of NHS Forth Valley
9	Nick Lewis-Barned	Consultant Physician, Diabetes and Endocrinology, Northumbria Diabetes Service
10	Professor Richard Thomson	Institute of Health and Society, Newcastle University
Session 3		
11	Karen Anderson	Director of Allied Health Professions, NHS Tayside
12	Peter Lerpiniere	Associate Director of Nursing for Mental Health, Learning Disability & Older People at NHS Borders
13	Joe McElholm	Head of Social Work Adult Services, Falkirk Council
14	John Stevenson	Head of Complaints Standards Authority

The Oversight Panel was anxious to ensure that a wide range of commentators were able to present to the Jury. To accommodate this, facilitators designed the following two different forms of commentator interaction.

a) The traditional one-commentator slot

The commentator was invited to talk for up to 15 minutes. At the end of their presentation the commentator was asked to leave the room to allow participants the space to talk with each other about their learning.

Participants were asked to think of any questions they would like to ask and these were written with marker pens on sheets of A4 paper. The commentator was then asked back into the room and asked the questions identified during the previous activity. Participants then decided if the questions should be asked by the facilitators or by themselves.

b) The speed dialogue

The speed dialogue sessions typically involved four commentators over the period of an hour. All Jury members were divided up and seated at a number of small tables, in this case four tables of six people. A commentator sat at each of the tables. The table commentator was then asked to spend a maximum of two minutes introducing themselves and how they relate to the Jury question.

This introduction allowed Jury members to identify relevant questions to pose to the commentator, and a dialogue developed that explored the issue or the perspective of the commentator in depth. After approximately 15 minutes the facilitators asked each commentator to move to the next table, where the process was repeated. This was repeated until all tables had been visited by commentators. In this way through a set of highly intensive dialogues, a large amount of information could be exchanged in a short time.

One of the facilitators spoke to each of the commentators in advance of their session to prepare them. During this briefing the following was explained.

- Each Jury member would be equipped with a red card. This would be a gentle reminder that commentators should at all costs avoid complex language and abbreviations. If a Jury member showed a red card it was merely an encouragement to explain in simple, clear language what was meant.
- Not everybody is comfortable with the written word, so commentators were asked not to use PowerPoint presentations. Sharing any reports or handouts with Jury members for them to take away was permitted. Jury members were encouraged to do this at the end of each round so as not to interrupt the conversation.

Time permitting, after each commentator slot, participants were given the opportunity to talk to each other about their learning.

Day one finished with participants reflecting on what topics they felt they would like to hear more about in sessions two and three.

Session 2

An Oversight Panel meeting between session one and two considered the suggestions of commentators from Jury members in session one and agreed the list of commentators for session two.

All Jury members who attended session one returned for session two.

Speed dating

Day two started with a further opportunity to develop relationships between fellow Jury members, share experiences, opinions and ideas and to recognise the wealth of knowledge that exists within the Jury itself (an attempt to make sure that the Jury values its own knowledge and is not purely reliant upon knowledge fed to it by the commentators).

This was achieved through a speed dating activity. Participants occupied two long rows of chairs (12 chairs in each row). Each person faced a fellow Jury member and was asked to spend one minute talking to the person opposite on *'any thoughts on shared decision-making and how it can be improved?'*

After the minute had elapsed it was the partner's turn to share their thoughts before the facilitator moved one row to the right to allow each person to repeat the process with a new partner. This continued for a further 20 minutes.

Following this introductory exercise the bulk of the second session was spent in dialogue with commentators.

Where do you stand?

The facilitation team were aware towards the end of session two that participants had taken part in a very intense and tiring day's work. They decided to slightly adapt the programme and introduce a final interactive and physical activity.

Facilitators suggested to the group that some of the small group and large group conversations and questions to commentators seemed to revolve around the following themes (although facilitators stressed this was not an exhaustive list).

- Senior people/leaders need to ensure shared decision-making is widely used.
- Training for healthcare professionals to encourage them to use shared decision-making.
- There needs to be independent people who can join the conversation between medical professionals and patients.
- Better prepare patients for their appointments so they can be more in control and ask the right questions.

The four themes were written on flipcharts and placed in the corners of a space set out for the activity. Jury members stood in the middle of the space and were asked to think about which of the issues they presently felt were most important in making sure that shared decision-making happens. It was stressed to participants that this activity was a way of encouraging discussion and debate and that there were no wrong or right answers.

After a couple of minutes of quiet reflection participants were asked to stand near their chosen flipchart stand. Facilitators then initiated a large group discussion where people talked through why they had chosen to stand where they did.

Session 3

Time is necessarily compressed in a three-day Citizens' Jury, as opposed to the more common long form Citizens' Jury (which takes place over more, but often shorter, sessions). The facilitators, with the agreement of the Oversight Panel decided to present to the Jury a set of themes that they believed (after consultation with some of the observers) were consistently surfacing throughout the first two days. Ideally this would have been a task completed by the Jury members themselves but the breadth of the topic, number of commentators and compressed format meant this was not an option.

Facilitators stressed that these could be changed and added to at any stage during the final day and should simply be seen as guides to help structure the Jury's conversations. Wherever possible, wording used by the participants themselves within earlier sessions was used.

The following themes were each assigned a table:

1. Services not communicating with each other - sharing information.
2. How appointments are run: (10 minutes too short, need for a 'cooling off' period before a decision is made)
3. Patients/service users being able to engage with and challenge professionals: (more information available. Access to medical records. Recording appointments. Self-advocacy training).
4. Having a neutral third person available/advocacy.
5. Training for professionals: (skills training, active listening etc).
6. Organisations making sure that shared decision-making happens: (culture change, leadership, valuing shared decision-making, finances, measuring shared decision-making, resources, systems).
7. Consistency: consistent service offerings nationwide (when all treatments are on the table all options can be considered). Achieving consistency of shared decision-making.
8. What if shared decision-making isn't happening?

Jury members were then asked to go into pairs to look at each of the themes and write on post-it notes what issues need to be discussed under each theme.

They were then asked to choose one theme to work on, to go to that table, look at what was written and then consider the following question: '*What extra information do we need to be able to write recommendations?*'

Facilitators explained who the final set of four commentators were going to be, and asked Jury members to consider whether or not any of the information gaps identified during the previous activity could be filled through questioning these commentators.

At the end of the final commentator speed dialogue everybody was invited to take five minutes for silent reflection to look at everything that was covered and then to write one draft recommendation on a piece of paper and finally place it under one of the themes (or an 'open' space titled 'other ideas').

Refining recommendations

After lunch participants were asked to go into the themed groups that most interested them and to start sharing ideas and writing down thoughts under that theme that might form the basis of a recommendation. Facilitators toured the tables to help those that needed assistance with converting their thoughts into a recommendation.

During the next part of the activity at least one person was asked to remain at their table whilst everybody else was free to move to different tables to look at the emerging recommendations written by others.

Jury members were then given a final opportunity to decide whether or not they wanted to receive any further external input before finalising their recommendations. Participants were told that 'Resource people' (see box on this page) were either available to answer questions on the phone or available in the room for the next 45 minutes.

Only one Jury member took up this offer and was joined by two others for a conversation with Joanna Swanson from the Scottish Government.

Jury members, working in small groups continued to refine and edit the recommendations until time constraints prevented any further iterations.

Session 3 resource people	
Professor Richard Thomson	Institute of Health and Society, Newcastle University
Shaben Begum	Director, Scottish Independent Advocacy Alliance
Pauline McFadden	Carer
Nick Lewis-Barned	Consultant Physician, Diabetes and Endocrinology, Northumbria Diabetes Service
Dr Graham Kramer	GP
Dr Julie McElroy	Campaigner on diversity and disabilities

Session 3 resource people	
Helen Mackie	National Clinical Advisor, Realistic Medicine, Consultant Gastroenterologist, NHS Lanarkshire
Gary McGrow	Social Researcher, Scottish Health Council
Joanna Swanson	Person-Centred and Quality Team, Directorate for Healthcare Quality and Improvement, The Scottish Government
Erica Reid	(Chair of the Oversight Panel) Associate Director of Nursing and Allied Health Professionals, NHS Borders

Voting on the recommendations

A total of 13 recommendations were written by the members of the Citizens' Jury in the refinement session. The recommendations, written by hand on pieces of A4 paper, were then stuck in a row onto one of the walls of the venue, with two rows of seats facing them, waiting to be occupied by Jury members.

While seated in front of the recommendation 'gallery' the group listened as one of the facilitators read out each of the recommendations in turn.

Participants were asked to confirm that they understood each recommendation and that it was clear.

Each member was then given their own anonymous voting sheet and asked to vote for their top seven recommendations (with each vote being equal and in no particular order).

In order to better understand the preferences of Jury members, participants were then asked to rank their top five recommendations. The ranking of the recommendations was undertaken by using a form of nominal group technique¹⁴ whereby Jury members prioritised their five most favoured recommendations 1 to 5. The recommendations were then ranked by aggregating the scores of all the Jury members (where 1= a score of 5, 2=4, 3=2, 4=1 and 5=1).

The table below is the complete set of recommendations for the Citizens' Jury and their voting.

¹⁴ https://en.wikipedia.org/wiki/Nominal_group_technique

Recommendations

The following recommendations have been written in the Jury members' own words and are unedited.

Rank	Recommendation	Theme	Score
1	<p>A programme to begin to inform and educate patients of their right to ask questions of their health professional and the benefits of doing this in terms of what they want and the best outcome for them. This would require investment and could be done in the following ways:</p> <ul style="list-style-type: none"> a) information leaflets or information monitors (screens) in GP surgeries should include questions that patients can ask: <ul style="list-style-type: none"> i) Is this test, treatment or procedure really needed? ii) What are the risks and benefits? iii) What are the side effects? iv) What are the alternative treatment options? v) What would happen if I did nothing? b) Introduce a questionnaire given to patients while waiting to see a health professional: are you aware of shared decision-making? Do you need any help from family or someone independent to help with the decisions? What questions do you want answered by your health professional? c) School visits to educate children about how to participate in shared decision-making by nurses or doctors. 	A	64

Rank	Recommendation	Theme	Score
2	There must be training for all health and social care professionals so that they use shared decision-making (e.g. active listening, people skills and an understanding of the need to share power and the dangers of hierarchy). This must happen for new and existing staff. Where relevant, this is part of the professional's registration renewal. Use of these skills must be monitored on an ongoing basis. Budgets and time must be made available for this to happen.	D	51
3	<p>There needs to be independent people who can join conversations between medical professionals and patients. This is often called advocacy:</p> <ul style="list-style-type: none"> • Social services, housing, carers and other agencies need to be proactive in enabling homeless and socially isolated people, or those that live alone to also have access to advocacy when engaging with health professionals. • There needs to be more information on advocacy to make it visibly available when people need it: who and where advocates come from, how to contact them, their reputation and skills including appropriate language and communication skills, empathy and ability to challenge. • We need to be exploring how incentives (paid or unpaid) could improve access to, independence of and quality of advocates in shared decision-making. <p>Advocates need to be able to be challenged and be accountable as they can have considerable influence over potentially vulnerable people.</p>	E	46
4	There should be a database online for all healthcare and social care professionals to access information about patient's history. Security to be agreed with patient's consent. This will make sure that all relevant past information is taken into account when shared decision-making is happening so improving the quality of decisions made.	F	29

Rank	Recommendation	Theme	Score
5	At all levels, there needs to be adequate finances, resources and support for shared decision-making. There must be the flexibility to move resources (e.g. budgets) to areas in need of improvement and support. However, the government needs to use whatever means to inform and educate all health boards to achieve consistency across all services in relation to shared decision-making, across all levels and areas of services e.g. the quality and principles of shared decision-making must be similar from medical professional to medical professional.	B	28
=6	All patients and service users need to be able to access their records (e.g. medical records) and test results so that they are more aware of what they want to discuss and what questions they want to ask. This will help patients and service users to feel empowered, confident and able to reach their ideal outcomes.	F	23
=6	Medical appointment times need to be more flexible as 10-minute appointments can be too short to explain problems and to question the professional about options for treatment.	C	23
8	<p>There needs to be some way of measuring if shared decision-making is taking place and if it is an improvement. This would help identify training needs for improvement. It would help to identify if it is being applied consistently and if it is successful.</p> <p>If this can be demonstrated the culture might change and patients, senior management in organisations and health professionals might be more invested in the process. For example: a clear visible and simple process for receiving feedback from those involved in shared decision-making (i.e. patients, medical professionals, advocates etc.). This feedback should allow for measurement and evaluation of progress, e.g. patients – do you feel you are listened to today?</p>	B	20

Rank	Recommendation	Theme	Score
=9	<p>There needs to be a culture of continuous improvement with regards to shared decision-making. Well-established individuals need to believe in the culture in order to support it and to encourage shared decision-making to be a part of company culture.</p> <p>i.e. managers supporting it may make employees more likely to support shared decision-making.</p> <p>There needs to be an individual or group/team in each district dedicated to shared decision-making. This team should be composed of both senior/experienced individuals and newer less experienced individuals.</p>	B	19
=9	<p>As patients we need the option to be able to see the same medical professional where possible. This means shared decision-making will be of a higher standard as a relationship has been built and the professional better understands the patient and their history.</p>	C	19
11	<p>Better prepare patients for their appointments so they can be more in control and ask the right questions:</p> <p>e.g. develop and create clear and concise information regarding conditions, illnesses, treatments, support and risks that can be easily accessed to better inform decisions and spark more constructive conversations with professionals.</p> <p>e.g. setup group therapy or shared sessions within a doctor's surgery to access further advice and peer support etc.</p> <p>e.g. have the option to email your doctor before an appointment so they know what your complaint (or condition) is (this would be time saving).</p>	A	16
12	<p>There needs to be more support when or if a power of attorney is required, this includes the cost. If not it can delay shared care or decision-making. Or find alternative ways to do it e.g. guardianship, living wills?</p>	E	13

Rank	Recommendation	Theme	Score
13	Create positions that can give face-to-face advice outside of a consultation, to take pressure off GPs and consultants whilst providing information to better inform decisions.	C	9

Recommendations were put into the following themed groups for discussion at the launch event.

A	Inform, educate and prepare patients to ask questions
B	Creating the culture for shared decision making including adequate finances, resources and support
C	The organisation of appointments
D	Training for professionals
E	Advocacy
F	Patient's information and records

Citizens' Jury Launch Event

On 6 February 2019 representatives from the Our Voice Shared Decision-making Citizens' Jury presented their recommendations to the Chief Medical Officer and a range of stakeholders.

Jury members met two weeks previously to discuss and agree a format for the event and to share roles and responsibilities. On the night, 13 of the Citizens' Jury presented to those invited. Different members of the Jury, many of whom had never spoken in public at such an event, explained the recruitment process, the role of commentators and the structure of the sessions as well as sharing personal stories to explain their motivation for participation.

The Chief Medical Officer, Catherine Calderwood, thanked the group and once again reiterated her commitment to respond to all the recommendations within three months. Some 40 people took part with a range of organisations represented including Jury commentators and Oversight Panel members as well as representatives of the Chief Nursing Officer Directorate, Falkirk Health and Social Care Partnership, the General Medical Council, the Health and Social Care Alliance Scotland, Healthcare Improvement Scotland, NHS Tayside, the Office of the Chief Medical Officer, the Office of the Chief Social Work Adviser, the Royal College of General Practitioners, the Scottish Health Council, Shared Future and the University of Dundee.

The final part of the evening involved all present dividing into a series of themed groups to consider some of the Citizens' Jury recommendations. Each table was facilitated by a combination of Shared Future and Scottish Health Council staff and considered a number of recommendations before attempting to answer the following questions: 'Why do these recommendations matter?' and 'How could the recommendations be implemented?'

A summary of these discussions is included in Appendix 3.



Next Steps

The Scottish Government has committed to carefully consider each of the Jury's recommendations and reply to them all, either with a commitment to action or an explanation as to why that recommendation cannot be taken forward.

The Chief Medical Officer will respond to these recommendations by May 2019.



Appendix 1: commentator sessions

Facilitators were not present at each of the roundtable discussions during the commentator speed dialogue sessions. As a result the questions asked by participants have not been recorded. However, the following questions were asked by participants of commentators during the sessions with only one commentator.

- How does shared decision-making work when a patient sees more than one healthcare professional over a problem?
- What systems do healthcare professionals have in place for the sharing of information over a patient's problem?
- Is there anything you feel personally would help ensure shared decision-making?
- Is there any way to enforce shared decision-making so that patients will receive consistent care?
- Doctors' training: what training is given to other healthcare professionals in relation to their interpersonal skills and shared care?
- How do you see the outpatient appointment system developing in the future?
- What would make it easier to communicate more effectively between professionals?
- Should shared decision-making be more than one-to-one, go to the top?
- How do you encourage patients to get involved with a shared decision?
- What are your opinions on a third party being present?
- Do you think telephone consultations would be helpful/time-saving?
- Do you think shared decision-making can be abused? (e.g. options that are cheaper for the NHS or families wanting to get rid of family members). How can we safeguard to stop this?
- What if everyone (all parties) comes to a different decision? Could having transcripts of the consultation prevent the patient not fully understanding the information/give them time to take in?
- Would having universal information about conditions and advice available help the process?
- Does shared decision-making come down to just cost and time?
- What may the strain of shared decision-making have on NHS resources? (The context is a system typically reported as already being very strained and underfunded).
- Who can you go to if you feel you haven't been involved in decision-making?

- How do healthcare professionals feel about shared decision-making?
- Is there training across the board for shared decision-making?
- How do you measure shared decision-making?
- How is misdiagnosis fed back to GPs so they learn from their mistakes?
- How do we tackle those GPs/health professionals who aren't doing shared decision-making?

Appendix 2: session plans

Realistic Medicine Citizens' Jury, Day 1: facilitators plan

Day 1	
10:00	Introduction from Shared Future facilitators (10 mins) Introduction and Question and Answer with commissioner: Erica Reid ¹⁵ (5 mins plus 15 mins Q and A) Video message from Chief Medical Officer: Catherine Calderwood (10 mins) Getting to know you activity I (People Bingo) (15 minutes)
11:00	Break
11:20	Getting to know you activity II (Human Map) (10 minutes) Activity 1: What does shared decision-making mean for you? What does it/could it look like?
12:15	Lunch
1:00	Activity 2: Digging deeper: problem trees
2:00	Break
2:15	Commentator slot 1: What is shared decision-making? Helen Mackie ¹⁶
3:10	Break
3:25	Commentator slot 2: Experiences of shared decision-making from the patient/service user experience: Julie McElroy and Andrew Cassidy
4:25	Reflection: what do we need to hear more about in session 2?
4:45	Close

¹⁵ Chair Oversight Panel, Associate Director of Nursing and Allied Health Professionals, NHS Borders, Chief Nurse Health and Social Care Partnership.

¹⁶ National Clinical Advisor, Realistic Medicine, Consultant Gastroenterologist, NHS Lanarkshire

Day 2	
10:00	Introduction: Ice breaker and reflection
11:00	Break
11:15	Commentator 1: Dr Graham Kramer
12:15	Lunch
1:00	Commentator speed dialogue A: Voice: Tommy Whitelaw, Pauline McFadden, Shaben Begum, Andrew Murray (15 min each at 4 tables of 6 people)
2:00	Break
2:20	Reflection
2:50	Commentator speed dialogue B: Professionals and systems: Nick Lewis-Barned, Professor Richard Thomson. (30 min each at 2 circles of 12 people)
3:50	Break
4:10	Reflection (completion of questionnaires)
4:45	Close

Day 3	
10:00	Introduction Our themes: what needs to be discussed under each theme / 'What extra information do we need to be able to write recommendations?'
11:00	Break
11:15	Commentator speed dialogue: Karen Anderson, Peter Lerpiniere, Joe McElholm, John Stevenson
12:20	Lunch
1:00	Draft recommendations: Working in themed groups sharing ideas and if ready starting to write recommendations. Identify any questions that need to be answered that will help make recommendations robust. Explain availability of commentators and resource people in the room if any external input is needed.
2:00	Break
2:20	Refine recommendations
3:10	Deliberation activity: stand next to the group of recommendations that you think, if they are implemented 'will improve the implementation of shared decision making' followed by facilitated large group discussion
3:35	Break
3:55	Clarification / editing of recommendations and anonymous voting
4:30	Evaluation
4:40	Close

Appendix 3 – Notes from themed discussions

Creating the culture of Shared Decision-making

This discussion group explored the importance of creating a culture that values shared decision-making and how 'culture is the most difficult thing to shift' but without it any strategy is undermined. Members of the group talked about the importance of a culture of openness and how 'all services could and should be more open to scrutiny and challenge, as this improves trust and accountability'. Such a culture must recognise the value of social justice and equity and requires the involvement of patients and citizens to shape services at the same time as recognising the imbalance of power.

The group explored how the recommendations could be implemented. They spoke about the need to challenge the hierarchy and end command and control cultures, to invest in shared decision-making, to shift conversations from medicine to good quality of life (realistic wellbeing, not realistic medicine), to avoid being hidebound to systems 'that leads to, for example, too short time to talk', to see 'shared decision-making as stress relief for professionals and to challenge the notion that 'unreasonable amounts of hard work are a badge of virtue'.

Conversation continued on the theme to reflect upon 'the five golden rules of shared decision-making; listen, prepare, relax, recognise (I must know the limits of my knowledge) and capture and share knowledge (learning comes from everywhere and everyone)'. The evening finished with a reflection that 'this conversation has been missing the voice of the middle ranks. Where are the perspectives of those operating at the point of care? Their views need respect too'.

Inform, educate and prepare patients to ask questions

The members of this discussion group talked about the importance of developing the public's confidence to ask questions and challenge healthcare professionals. The conversation focused particularly on how the recommendations could be implemented. The healthcare system should look at examples of good practice already happening in other organisations and learn from these.

For citizens to feel sufficiently empowered to ask the questions listed in recommendation one, it could be policy that all outpatient letters include these key questions, as well as them being regularly displayed on the monitors in GP surgeries. The conversation also considered how complex language can be disempowering for the patient and that there should be gaps between interventions to allow patients to reflect. The group considered whether people know about the Patient's Charter of Rights in helping people to

navigate their way through this complex field. It was suggested that we must use other resources in the community; Citizens Advice Bureau, NHS websites, Patient Advice and Support Service (PASS) etc.

The organisation of appointments

The participants in this themed group felt these recommendations matter because firstly, dealing with a different doctor at different appointments means more time is taken up to re-explain the situation which in turn leaves less time for shared decision-making, Secondly, some people attend appointments to 'test the water' with the doctor and after a period of contemplation (figuring out what's wrong) go back to the doctor to make a decision – this gets complicated if it's a different doctor, thirdly, research shows more continuity equals better care.

The discussion then moved on to consider how best the recommendations could be implemented? Ideas included: more serious or complex care is undertaken by a doctor and less complex care is undertaken by a nurse or other professional, that there should be more links workers with a coaching and signposting role, shared patient clinics or joint consultations to allow group discussion on how a condition can be self-managed. The need for the monitoring of and sharing of good practice on shared decision-making was also highlighted.

The group also considered how the patient could make the decision on when next to make an appointment rather than the appointment being made for them and how long they need – this could even be a phone call rather than travelling to a face-to-face meeting.

Training for professionals

The Citizen's Jury members talked about their variable experiences of shared decision-making – sometimes it's been positive, other times not. Consistency is important and the training of health and social care staff should help achieve this. Patients need to be feel informed and be able to trust the healthcare professionals providing their care.

The group then considered how these recommendations could be implemented. As part of the General Medical Council (GMC) outcomes for their graduate training, medical students now receive training all the way through their course about how to communicate well with patients – including the principles of shared decision-making. They have consultations with patients observed to ensure their patients are included in decision-making and they must undertake courses and learning modules. This level of training should be extended to other healthcare professionals.

The group talked about the need to use structures that are already in place to make this happen e.g. the revalidation process for some healthcare professionals and the need to build strong evidence of shared decision-making into this process.

Staff training on shared decision-making needs to be developed and implemented for all health and social care staff and not only regulated professionals. It should include, for example, healthcare assistants (who it is recognised are often the staff members who patients speak to the most), care home staff and anyone else who communicates with patients and their families. Staff can be evaluated by managers and team leaders to ensure they are involving patients in decisions about their care. That shared decision-making is a part of an organisation's culture could be evaluated through inspections and audits carried out by bodies such as Healthcare Improvement Scotland and The Care Inspectorate.

Through collective leadership, people at the grass roots also need to push upwards to say what they want to see happen and professionals should use tools that are already available, and which help provide solid evidence of the benefits e.g. Care Opinion.

Patients' information and records

This group discussed this issue and how its timing follows the Scottish Government's publication of the 'Scotland's Digital Health and Care Strategy: Enabling, Connecting and Empowering' in April 2018. The strategy contains a commitment to produce a national clinical platform for clinicians but also that there should be access for patients to their own information. This is a foundation stone of shared decision-making.

The healthcare professionals round the table were positive about the Citizens' Jury idea that an App or 'roadmap' could be developed to help patients know where to access information.

The group felt that examples of good practice should be shared more widely, for example, kidney patients receiving treatment at Dundee's Ninewells Hospital are provided with a 'patient view' document which gives them valuable information on their own treatment and care. Another positive example is the Pain Clinic at Ninewells Hospital. The experience of one Citizen Jury member, who had been provided with monthly updates in visual form which propelled her to ask questions of her doctor and take control of managing her own health, was also highlighted.

Further discussion considered how information recorded in the patient's record should be written in lay terms and not in clinical terminology. Being mindful that at any time the patient may wish to read their own record should encourage professionals to think carefully about the terminology they use and to not write anything they would be unhappy for the patient to see. In certain specialisms (e.g. social work) this already happens because the professionals are aware that records can be requested or accessed at any time. Therefore, they need to be aware of what is being recorded from the onset.

Concern was raised about the length of time it can take to share information with a patient e.g. test/scan results. At times the results have been with GP or consultant for some time. This causes the patient and their family concern and worry.

The group concluded that healthcare professionals need to ask patients how they personally wish to receive information relating to their health. This recommendation should be the end goal – ultimately the information belongs to the patient and it should be available in accessible language and a format the patient can engage and interact with.

Advocacy

Jury members shared their experiences of chancing upon the option to engage an advocate. They found the outcomes worthwhile but the act of engaging to be down to chance rather than process or professional direction. There was no clear or advertised route to access advocacy – they 'found out' about these services anecdotally e.g. from family members and friends who highlighted their availability.

The group talked about why independent advocacy, as a third party who could stand alongside people and help articulate their point of view, is important. 'Someone to speak for you.' They are 'people who listen', who remove or lessen 'vulnerability by having someone to speak for you'. They translate/interpret and improve communications between professionals and people in a health/welfare context and ensure the patient voice is forefront.

The group went on to talk about how advocates help you find the right questions to ask. Where advocates have situation knowledge they can signpost or introduce people to other organisations/people who could help, they also help people be aware of what to ask, what options are open to them and to understand possible consequences of each option.

The group also talked about:

1. How adding an independent third person to the professional-patient conversation can save resources by enabling professionals to make better informed decisions (as they would have a fuller understanding of people's needs).
2. How advocacy is important for '*ensuring equality*' for vulnerable people '*when they need support most*'.
3. That access to and knowledge about advocacy is inconsistent across the country – knowledge of advocacy services is perceived to be low, referral or recommendation via healthcare professional to advocacy is perceived to be low, and availability of advocate is perceived to be extremely patchy according to geography or health issue.
4. Jury members who had used advocacy services indicated that they found out about them through chance rather than through referral or through conversations with professionals.
5. Personal experience of advocacy via Citizens Advice Bureau – found out by chance.

The small group then went on to consider how the recommendations might be implemented.

1. Signposting to advocacy services should be improved. Many *healthcare professionals might not know of these and could benefit from* training to be able to look for signs of need for advocacy.
2. Improve awareness via advertising of services: '*Technology could be used to advertise*' (e.g. TV screens/billboards in GP surgery or hospital, leaflets, Patient Advice and Support Service (Citizens Advice Bureau) could be more prominent.
3. Can family members be advocates? Vulnerability still needs to be accounted for via robust checks/balances and training quality assurance needed.
4. Potential to utilise multidisciplinary healthcare professional retirees as advocates (they know the language and sources of further help).
5. Increasing availability of advocates still needs to be balanced by ensuring quality assurance, adequate training. May face difficulty managing increased demand whilst ensuring appropriate training of advocates.
6. Independent voluntary organisations currently arrange advocacy – should it be developed in general practice?
7. Quality assurance of the advocate role to ensure fair and equitable service.
8. Use of advocates can help use time and resources effectively – discussion occurs, this is rethought and reflected upon externally before conclusions are drawn – so it helps professionals and patients have fuller knowledge and make more informed decisions, thus reducing resource waste.

Power of attorney

Jury members and stakeholders shared their experiences of undertaking power of attorney and found the processes difficult and costly but the '*peace of mind*' it provided to be worthwhile. It was considered an important step to be taken in advance of ill health, a '*preparation*' to provide '*peace of mind*' to ensure the legal right to make decisions for a person if they can't make decisions for themselves. Power of attorney is a legal process and as such Jury members raised concerns about access barriers such as awareness, complex language, daunting process of arranging this (engaging solicitors/doctors) and its associated costs/fees. Given its importance, there was concern that it is not known about or used widely and is not routinely brought to people's attention. Since power of attorney is a process undertaken whilst people have the capacity to 'grant' this, it is important people have this preparatory knowledge.

The group went on to talk about how awareness of the need for power of attorney is low. One Jury member noted family members used to be able to make decisions, but the law changed and kinship no longer has the 'right' to decision making and that not everyone is aware of this. Often complex language is used and the potential need to consult a solicitor could deter people from seeking help (an 'attorney' is a type of solicitor as well as a person acting as a power of attorney).

Financial costs are important – there is a fee to register a power of attorney with the Office of the Public Guardian. Exemptions exist but must be applied for and so are potentially off putting and inequitable. Cost exemptions should be more widely advertised and more easily accessed.

The different options around the right to health decision-making are confusing – power of attorney vs guardianship vs living wills. Guardianship can take months to arrange and it's costly to go to court.

The group talked about the complexity of power of attorney and how people need capacity to understand and to grant it. Legal safeguards are there for good reason, but it needs simplifying.

The group's discussion concluded with a conversation on how these recommendations be implemented:

- Financial cost barriers could be removed – legal aid. Removal of financial cost or automatic exemption from costs rather than application for this.
- Simplify the system. Currently you must be registered with the Office of the Public Guardian, could it potentially be less formal if you could register instead with your GP? Vulnerability still needs to be accounted for via robust checks/balances and legal safeguards. Simplify the language – an attorney can be a lawyer and so this can bring misunderstanding to the concept.
- Improve awareness of services – billboards in GP surgeries. Citizens Advice Bureau was indicated as a source of information on advocacy and power of attorney.
- Power of attorney – concept of a named person (that is used in mental health). Could this be extended?

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

The Scottish Health Council
Delta House
50 West Nile Street
Glasgow
G1 2NP

0141 241 6308
enquiries@scottishhealthcouncil.org
www.scottishhealthcouncil.org/ourvoice.aspx