

Evaluation of the Our Voice Citizens' Jury on Shared Decision-making

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1 Executive Summary

A Citizens' Jury was commissioned in May 2018 jointly by the Scottish Health Council and the Chief Medical Office of the Scottish Government 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.

This evaluation was conducted by the Scottish Health Council to determine the learning from the Citizens' Jury and assess short-term impacts.

The question the Citizens' Jury was asked to answer was:

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.

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

This evaluation was conducted by asking feedback from key stakeholders that either took part in the Jury or took part in planning the Jury process.

Planning, administration and costs

A significant amount of planning and administration was required to ensure the Jury process went ahead and was well organised. This included procurement of independent facilitators; arranging the venue; recruiting the Oversight Panel, Jury members and commentators; and reporting on the process and outcome of the Jury. The overall cost of the Jury was approximately £31,000 which covered facilitator's fees, Jury recruitment costs, Jury member participant fees, expenses and venue fees.

Recruitment, diversity and retention

There were many more applicants than expected, and the recruitment and selection resulted in good diversity of Jury members. The main motivations for Jury members taking part were an interest in the topic of shared decision-making; to make a positive difference; and the financial incentive. The demographics of the Jury members that were recruited very closely matched the profile the Oversight Panel recommended and compares favourably with a cross section of the Scottish population for a group of 24 people. The 24 members of the Jury that started the first session stayed until the end of the process. Reasons for the strong retention could be attributed to the following:

- there was strong interest in the topic
- Jury members felt the financial incentive was “about right” (this was the view of 23 out of 24 members), and
- the venue location, accessibility and facilities were well regarded.

The length of the Jury process was considered to be about right for most Jury members. This included the length of each session (6 hours and 45 minutes with breaks), the number of sessions (three) and the time in between sessions (two weeks). The overwhelming majority of Jury members said their time was well spent.

Jury members and commentators felt that there was good facilitation and deliberation throughout the process, however some feedback suggested there could have been more facilitators and some more time for deliberation at certain points of the process.

Commentators (expert witnesses)

The commentators that took part in the evaluation said they were motivated to take part in order to put their perspective of shared decision-making across to the Jury members and also to find out more about, and take part in, a Citizens’ Jury.

Most commentators felt they had received effective support to take part, such as appropriate information and communication, although a few felt they could have benefited from some more support.

On average, commentators spent around 12 hours preparing for and taking part (including travel) in the Citizens’ Jury. This ranged from six to 21 hours and all commentators felt this amount of time was “about right”.

The overwhelming majority of Jury members felt that:

- they were able to ask questions of the commentators
- questions were answered to their satisfaction
- there was a good spread of opinion from commentators, and
- the commentators provided useful information.

The majority of the commentators fed back that:

- their interaction with Jury members was positive
- they were free to explain their own views on shared decision-making without undue influence from facilitators or sponsors, and
- their participation in the Citizens’ Jury added to their knowledge on shared decision-making.

Areas for improvement included more time for commentators’ sessions, more support for commentators to feel a part of the Jury process, and more focus on social care as well as healthcare.

Responses to the Jury recommendations

When asked whether the Jury developed reasoned and justified recommendations most Jury members felt that the recommendations were fully reasoned and justified. All Jury members that responded to the evaluation were positive about the Jury and its recommendations. Comments included how the Jury arrived at the recommendations in a democratic way and there were positive comments relating to the diversity of the Jury.

Commentators mainly found the Jury's recommendations thoughtful, positive and intelligent.

Chief Medical Officer response to recommendations

The Chief Medical Officer, Catherine Calderwood, wrote positively about the impact of the Citizens' Jury in her annual report, *Personalising Realistic Medicine*, published in April 2019, saying:

“The Jury has been a fascinating and most valuable exercise that has given us the opportunity to reflect on how we can get better at shared decision-making.”

Feedback on Scottish Government response to recommendations

The Scottish Government published its response to the Citizen's Jury recommendations at the end of May 2019.

Eight out of the nine Jury members that responded to the evaluation questions relating to the Scottish Government's response strongly agreed or agreed that the it appropriately addressed the Jury's recommendations. The feedback from commentators was more mixed, with six of the nine that responded agreeing that the Scottish Government's response appropriately addressed the Jury's recommendations, with one disagreeing and one strongly disagreeing.

Impact on the Citizens Jury members

All Jury members that responded to the evaluation (23):

- would recommend to family and friends to participate in a Citizens' Jury
- thought that Citizens' Juries are a good way to involve the public in decisions about health and social care, and
- were willing to take part in another Jury on a different topic.

Impact on shared decision-making work programme

The Scottish Government's response to the Jury's recommendations validated existing policies and work programmes on shared decision-making, as well as informing new work.

New pieces of work which the Citizens' Jury output has directly influenced include:

- the further development of a set of question prompts that can be used to promote shared decision making when a patient has an appointment with a healthcare professional, and
- the development of an educational module on shared decision-making.

Conclusions

This evaluation concludes that the aims of this Citizens' Jury were largely met successfully. There is more evidence to support the successful implementation of the Jury process, rather than the impact of the Jury, although it is recognised that it is early days in terms of implementing the Jury's recommendations.

Overall, having commissioned and evaluated this Citizens' Jury, the Scottish Health Council concludes that a Citizens' Jury is a valuable tool to capture public involvement in health and social care in Scotland. It is an approach which can engage people and provide informed insight on a topic from a cross section of the public.

2 Introduction

In May 2018 the Scottish Health Council and the Scottish Government commissioned a Citizens' Jury on the topic of shared decision-making. This report sets out learning from the Citizens' Jury and reports on feedback from some of the key stakeholders in the Citizens' Jury process. These stakeholders were:

- Jury members
- the Oversight Panel
- the Implementation Group, and
- commentators (expert witnesses)

The evaluation report also highlights short-term outputs and impacts from the Jury. This evaluation report should be read in conjunction with the Our Voice Citizens' Jury report¹ and the Scottish Government's response to the Jury's recommendations².

¹ http://scottishhealthcouncil.org/our_voice/citizens_jury.aspx

² <https://realisticmedicine.scot/citizens-jury-recommendations/>

3 Background

3.1 Reasons for establishing the Citizens' Jury

Citizens' Juries involve the bringing together of a diverse group of members of the public to work through a complex issue. Jury members draw upon their personal opinions and experiences as well as the knowledge and opinions of a range of experts before producing a set of recommendations. These processes are now widely used in many countries across the world as a way of involving members of the public in decision-making.

The Citizens' Jury on shared decision-making was established as part of the Our Voice³ programme which was developed to support people and their families to engage at every level in health and social care. The Jury was established as a test of change to learn from more deliberative methods of engagement as well as informing the work of Realistic Medicine.

In 2017 the Chief Medical Officer announced in her annual report, Realising Realistic Medicine⁴, plans to convene a Citizens' Jury to help implement the vision of Realistic Medicine. Subsequently, the Scottish Health Council was asked to manage and evaluate a Citizens' Jury on the topic of shared decision-making. After a competitive tendering process in the summer of 2018, the contractor Shared Future⁵ 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.

3.2 Summary of Citizens' Jury Process

Shared Future was recruited to facilitate the Jury. An Implementation Group consisting of representatives from the Scottish Government, the Scottish Health Council and Shared Future was formed. Its role was to manage and implement the activities required to make the Jury happen and act on the guidance of the Oversight Panel.

³ http://scottishhealthcouncil.org/our_voice/our_voice.aspx

⁴ <https://www.gov.scot/publications/chief-medical-officer-scotland-annual-report-2015-16-realising-realistic-9781786526731/>

⁵ <https://sharedfuturecic.org.uk/>

The Oversight Panel, consisting of stakeholders from Scottish Government, health and social care, academia, third sector and lay representatives, was established to:

- ensure that the Jury process is fair and rigorous
- agree on the final form of the question to be posed to the 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.

The Oversight Panel met on five occasions in Edinburgh, including at the start of the Jury process, between Jury sessions and after the final session. 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. A few questions were put to the Oversight Panel and, after deliberation and discussion, the Panel agreed the question the Citizens' Jury was to answer was:

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.

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

The Scottish Government made a commitment 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 could not be taken forward.

The Jury was recruited via a letter sent to a random sample of residents drawn from the electoral register within a 45-50 minute travel time of Perth. Three thousand letters were sent out using the Chief Medical Officer's letterhead and participants were encouraged to respond by providing some of their demographic details via either a prepaid envelope, web link, or by telephone. Jury members were offered £100 attendance fee for each of the three days of the Jury as well as travel expenses and, where necessary, caring expenses in recognition for their time and effort.

The aim was to recruit a cross section of Jury members with demographics determined by the Oversight Panel. Quotas were set for age, gender, ethnicity, geography and those that have a long term health condition. The aim was to recruit 26 Jury members with the understanding that some members may drop out. Twenty-four (24) members attended the first Jury day and then went on to attend all further Jury sessions.

The Jury met in Perth during October and November 2018 on three separate Saturdays with two weeks between each meeting. 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. This included involving 14 commentators (expert witnesses) in the Jury process to give information to, and answer questions of the Jury members.

The Jury's recommendations were launched in Dundee on 6 February 2019 when a selection of the Jury members presented their findings to the Chief Medical Officer and health and social care stakeholders. For a full account of how the Jury was conducted please refer to the Our Voice Citizens' Jury on Shared Decision-making report and The Scottish Government response to these recommendations.

4 Evaluation method and approach

The Scottish Health Council developed an evaluation framework for the Jury which was presented to the Citizens' Jury Oversight Panel in October 2018, prior to the Jury being conducted. The Oversight Panel agreed to adopt the framework which aimed to gather learning on the Jury process and outcomes, including:

- recruitment and selection of Jury members
- facilitation and deliberation
- size and length of the Jury
- expert input and role of the commentators, and
- the recommendations.

The evaluation was conducted by asking key stakeholders who were involved in the Jury process to complete an evaluation survey. Feedback on the extent to which Jury members agreed or disagreed that "shared decision-making is a good idea" was tracked at the start and end of each Jury session. Jury members were also asked to complete an evaluation form at the end of the third Jury session in November 2018 and all 24 Jury members completed this. The evaluation questions focused mainly on the process of being involved in the Jury.

Jury members were then sent a hard copy of the Scottish Government's response to the Jury recommendations in July 2019, and were asked to complete an evaluation form which focused on Jury members' thoughts on the Scottish Government's response. A pre-paid envelope was included and two follow-up emails were sent to all Jury members reminding them to complete the evaluation either using the hard copy, or via a link to an electronic survey. A total of nine responses from Jury members were received.

Evaluation forms were also sent to the other key stakeholders in the Jury process in July 2019 as detailed below. Stakeholders were given six weeks to respond and a number of reminders were sent.

All 14 commentators were sent an electronic evaluation survey asking them questions on how they found the Jury process and what they thought of the Jury recommendations and response from the Scottish Government. Ten responses were received.

An electronic survey was sent to the eight members of the Oversight Panel who had participated in two or more of the meetings (and who were not Scottish Government officials), asking questions about the Jury process as well as the process of being on the Oversight Panel. Three completed forms were received.

Evaluation forms were also sent to the remaining four members of the Implementation Group and two completed forms were received.

5 Evaluation – key findings

5.1 Planning, administration and costs of establishing the Citizens' Jury

Planning

The Oversight Panel met on five occasions throughout the Jury process. Panel respondents generally felt that there was a good mix of people and that the Panel challenged the process from time to time.

“Think it was a good mix of people with service experience, user experience and academic knowledge. Along with people supporting in policy roles.”

Some Oversight Panel members were not able to make all the meetings, which meant that on occasion there was a lack of consistency in the discussion.

“Maybe didn't leave ourselves long enough time for discussions, but this is always balanced with how much time people can commit to attending meetings.”

“A more regular attendance and perhaps more information between meetings.”

One of the challenges faced by the Oversight Panel was recruiting commentators at short notice.

“Think the challenge with commentators was getting people at short notice and also at a weekend. Given these constraints I think we did well to field appropriate commentators.”

Comments from members of the Implementation Group about the Oversight Panel process included:

“We received useful challenge and fresh insights from the Oversight Panel. Given the issue ... it was harder to get divergent opinions onto the Oversight Group. A politician, for example, with responsibility for scrutiny and oversight of the health sector may have been a useful addition.”

“Oversight Panel worked well, perhaps needed to be convened earlier in the process but challenged the Implementation Group in places. Difficult to get people who didn't agree with Shared Decision-Making on the Oversight Panel.”

Administration

A significant amount of administration was required to ensure the Jury process went ahead and was well organised. When establishing a Jury, consideration needs to be given to the following (all of which were conducted during this Jury):

- determining an appropriate question

- procurement and managing contract with independent facilitators
- administration of Oversight Panel
- venue hire
- jury recruitment
- contact with Jury members before the facilitated sessions to make members comfortable and ensure they are focused on the task at hand
- travel expenses and carer expenses
- evaluation forms
- equality monitoring forms
- consent forms (covering consent to participate in the Jury as well as consent to have photographs taken)
- payment of participation fee
- recruiting and organising commentators, and
- reporting.

Costs

The total costs for the Jury came to around £31,000. Expenses are highlighted in the table below.

Expense	Costs (£)
Facilitators Fees	12,500
Jury recruitment costs	4,500
Participant fees	8,250
Participants & commentators expenses (travel, support for care arrangements)	2,360
Venue fees	3,300
Total	30,910

These costs don't include staff time for Scottish Health Council or Scottish Government employees, which for the Implementation Group (four members of staff) was considerable at key points in the Jury process.

Facilitators' fees included the contract for the work conducted by Shared Future which covered:

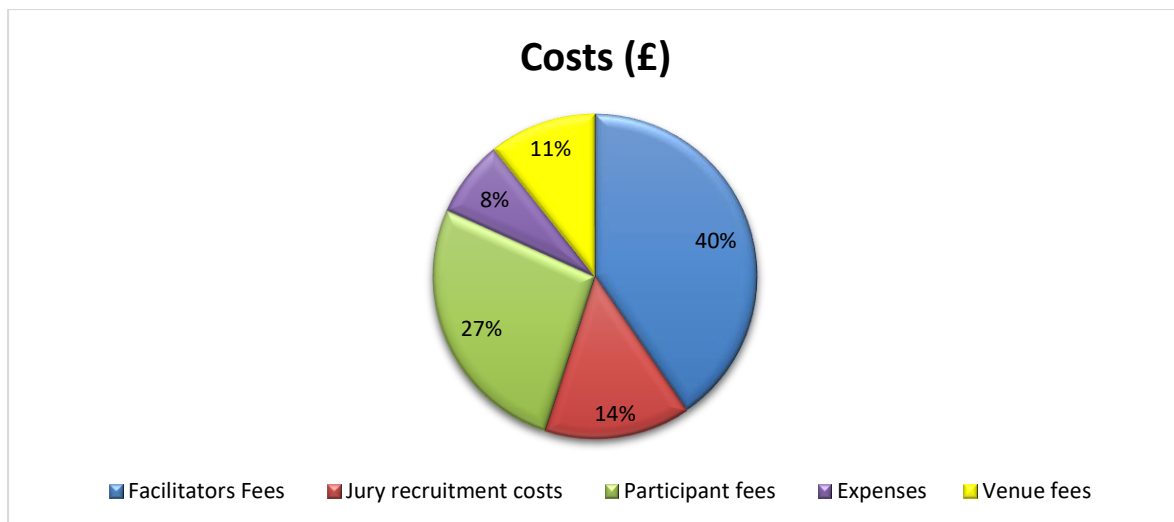
- planning meetings
- advice and guidance
- facilitation of Jury meetings
- contact and briefing of Jury members and commentators outwith meetings

- administering fees and expenses to Jury members, and
- writing the report.

Jury recruitment costs were total fees paid to Research Resource, a market research agency, which recruited the Jury members. This included printing and postage fees for the 3,000 letters sent out and recruiting the Jury members in line with the Oversight Panel’s guidance.

Participant fees included £100 per full session during October and November at the main Jury meetings, as well as £35 each for two evening meetings. One evening meeting was to prepare for the launch of the recommendations and the other was the launch event (although not all Jury members attended these).

In addition to fees, there were Jury and commentator travel expenses, as well as care expenses. The venue fees included three full day meetings in Perth with refreshments, as well as two evening meetings in Dundee.



5.2 Recruitment, diversity and retention of Jury members

Recruitment

Letters highlighting the purpose of the Citizens’ Jury were sent out to a random selection of 3,000 people on the electoral register. Letters were sent to people within a 45-50 minute travel time of Perth. Two hundred and sixty-nine (269) responses of interest were received, which was a 9% response. The response is favourable compared to the Our Voice Citizens’ Panel⁶, which received around 2-3% response. The good response rate could be put down to the following:

⁶ http://scottishhealthcouncil.org/our_voice/citizens_panel.aspx

- a financial incentive of £100 + expenses for each of the three sessions
- a letter written and signed by Chief Medical Officer on headed paper
- the Scottish Government commitment to respond to all the recommendations determined by the Jury, and
- all Jury members within reasonable travel distance of the venue in Perth.

Half of the Jury members (12) felt that of purpose of the Jury was fully explained to them and half felt that the process was explained to some extent. Only three members required further information or support to take part.

“I was worried it was going to be very formal and daunting but was reassured otherwise.”

Jury members were asked what motivated them to take part. The most common reasons given were:

- interesting topic/curiosity (12)
- to give something back/make a difference (8), and
- financial incentive (3).

Diversity of Jury members

The Oversight Panel set quotas for recruiting Jury members based on a demographic spread of the Scottish population. In addition, some demographic characteristics were over recruited (such as younger people and ethnic minorities) with the intention that there would still be a good cross section of the population on the Jury in the event that some members with these characteristics dropped out.

The data below highlights the demographics of Jury members and compares these with a Jury of a similar size if it were a statistical cross section of the Scottish population, as well as with the Oversight Panel’s proposed demographics. As can be seen from the three columns, the actual Jury that attended is in very close symmetry to both the Scottish population and the Oversight Panel’s recommended Jury. The areas in which Jury members lived covered three NHS Boards: Tayside, Fife and Forth Valley and five Health and Social Care Partnership areas: Angus, Dundee, Perth and Kinross, Fife and Clackmannanshire and Stirling.

Recruitment profile	Profile as a proportion of Scottish population ⁷	Original profile proposed by Oversight Panel	Actual profile of those in attendance at all 3 sessions
Age			
16 to 25	3	6	4
26 to 44	7	6	5
45 to 64	8	6	7
65 and over	6	7	8
Gender			
Female	12	13	12
Male	12	12	12
Scottish Index of Multiple Deprivation			
1 (most deprived)	5	6	6
2	5	6	5
3	5	5	5
4	5	4	4
5	5	4	4
Urban / Rural			
Urban	20	20	17
Rural	4	5	7
Long term physical/mental health condition			
Yes	11	10	9
No	13	15	15
Ethnicity			
Ethnic Minority	3	2-4	3
White British	21	23-21	21



Members of the Citizens Jury, Perth, November, 2018

⁷ Source: Scotland's Household Survey 2017. National Records of Scotland, Crown copyright. Retrieved from: <https://www.gov.scot/publications/scotlands-people-annual-report-results-2017-scottish-household-survey/>

Jury member retention

Twenty-four (24) members attended the first session and stayed through the process to the end of the third session.

The Implementation Group had anticipated attrition (i.e. people dropping out) along the way, but there were none. Shared Future, who are experienced facilitators and organisers of Citizens Juries, stated that this was a rare occurrence in such projects. Reasons for the strong retention could be due to the following factors.

- Jury members found the topic interesting and were motivated to the end.
- Good facilitation and members bonded well.
- Location and venue were regarded well.
- Financial incentive was the right amount (and paid at end of day three).

Evidence for the above statements include the following feedback from the Citizens' Jury member evaluation questionnaire:

Interest in the topic

Almost all Jury members (23) felt that the topic of shared decision-making was a good topic for a Citizens' Jury. One member was unsure.

"It's something that affects us all and everyone can bring their experience to it."

Motivation to take part

Jury members were asked what motivated them to take part. The most common reasons given were:

- interesting topic/curiosity (12)
- to give something back/make a difference (8), and
- financial incentive (3).

"It was something that interested me and I felt privileged to be asked to participate and have the chance to share my views and ideas."

"Interesting topic, being paid, something other than the 'day job', something different."

Financial incentive

Jury members were asked whether the financial incentive to take part (£100 per session) was too much, too little or about right. Only one Jury member felt it was too much and the other 23 felt it was about right.

Venue

The venue in Perth was generally regarded as very good or good, for the following aspects:

- Venue location – 20 Jury members rated very good/good
- Venue accessibility – 22 Jury members rated very good/good, and
- Venue facilities – 15 Jury members rated very good/good.

Length of Jury process

Most Jury members felt that the amount of time dedicated to the Jury was about right. The Jury consisted of three one-day sessions on a Saturday spread over three weekends, with two weeks between each meeting. Almost all (21) Jury members felt the length of each session was about right (10am – 4:45pm), whilst two felt it was too long and one felt it was too short. Most members (18) felt that the time between each Citizens' Jury meeting (two weeks) was about right, whilst the other 5 who responded felt it was too long. Overall, 23 Jury members felt that the number of meetings (three) was about right whilst one member felt there were too few.

Jury members were asked whether their time was well spent. Eighteen (18) members felt their time was "definitely well spent", five members felt it was "well spent to some extent" and one member was "unsure".

Some comments on improvement to the timescale of the Jury included the following comments:

"Trying to come up with recommendations over 3 sessions and over an extended period wasn't enough time to go into better detail of what could be done."

"I really enjoyed taking part but every Saturday would have been better for continuity fresh in the mind."

"The 15 minute interviews [commentators' sessions] would have been better as 20 minutes."

Facilitation/deliberation

There were a number of phases to the facilitation and deliberation including:

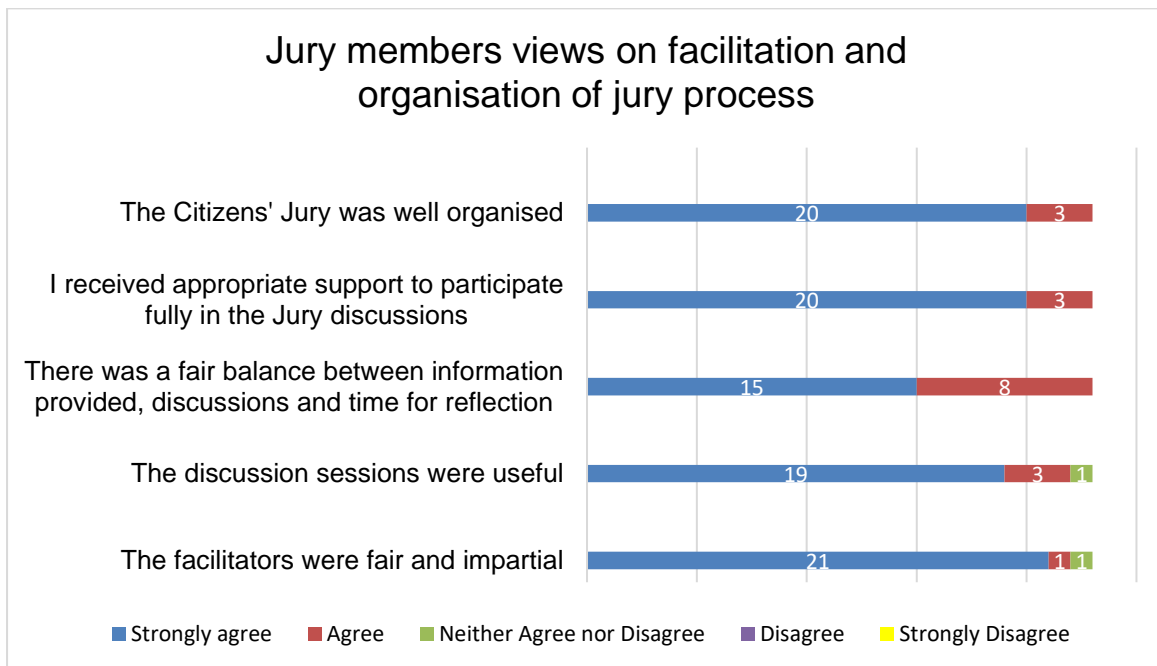
- an 'icebreaker' phase at the beginning in order for Jury members to get to know each other and comfortable talking about the subject
- exploring the question
- reflecting and deliberating on the topic of shared decision-making, and
- developing recommendations.

Twenty-two (22) out of 23 Jury members that answered the evaluation questionnaire stated that they strongly agreed or agreed that:

- the facilitators were fair and impartial, and
- the discussion sessions were useful.

All Jury members that responded (23) strongly agreed or agreed with the following statements:

- There was a fair balance between information provided, discussions and time for reflection.
- I received appropriate support to participate fully in the Jury discussions.
- The Citizens' Jury was well organised.



“Very well organised, very friendly.”

“Facilitators were excellent, keeping everyone involved and meetings on track.”

“Really worked hard, icebreakers were good and effective.”

Nine out of the 10 commentators that responded felt that the session they attended was appropriately facilitated.

“Well facilitated giving clear guidance to us as commentators and allowing the process and discussions to flow freely.”

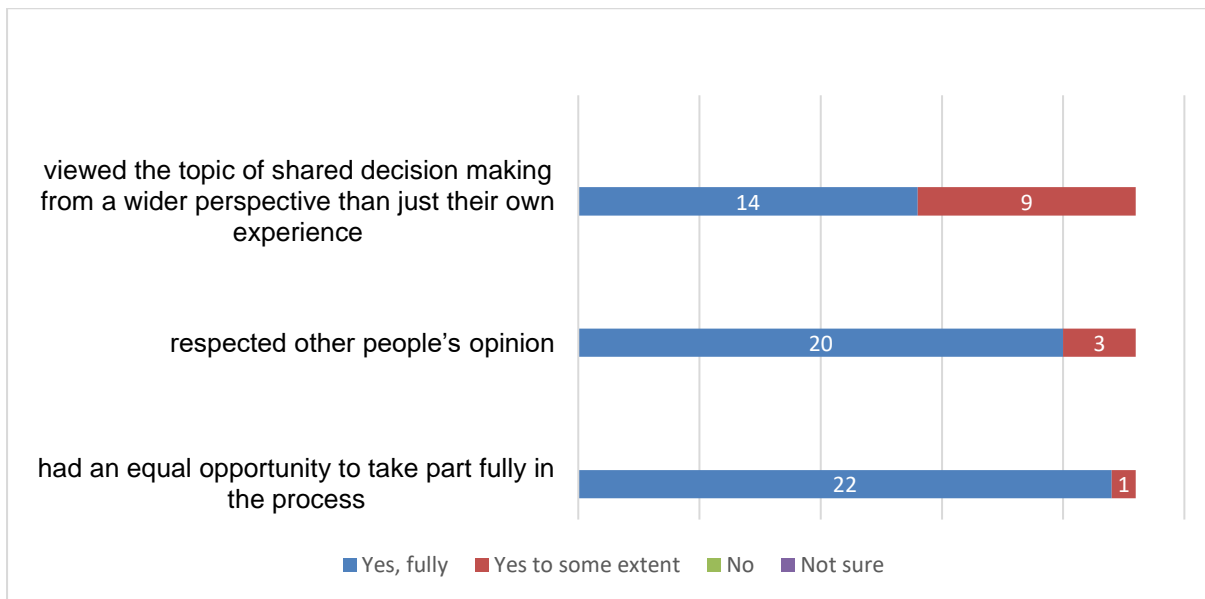
“Excellent facilitation, very interesting and worthwhile process and there was clearly flexibility and the ability to be responsive to how the group and their thinking was developing.”

“Yes, however trying to explain complex subject matter and answer questions in 15 minutes is tough. I think each table felt they could do with more time.”

In relation to the last quote above, this point was picked up by some members of the Implementation Group who felt this session would have been better with more time and additional facilitators to support the deliberation and discussion.

The overwhelming majority of Jury members felt that they had:

- an equal opportunity to take part fully in the process
- respected other people’s opinion, and
- viewed the topic of shared decision-making from a wider perspective than just their own experience.



5.3 Commentators

Another key feature in most Citizens’ Jury practice is the inclusion of 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 a legal jury.

The commentators were asked what motivated them to take part in the Citizens’ Jury. Ten (10) commentators out of the 14 who took part in the process responded with feedback to the evaluation. All commentators that responded advised they were happy to have been asked to take part in the Citizens’ Jury. Most were keen to put their perspective of shared decision-making forward to Jury members and also to find out more about, and take part in, a Citizens’ Jury.



Citizens' Jury during a commentators' session, Perth, November 2018

"I was happy to receive an invitation - was keen to have the opportunity to highlight and share with Jury members the connections across integrated health and social care agendas."

"I am supportive of engaging citizens and patients in helping define what is important ... I felt I had expertise to offer and was also curious to know how the process worked."

Most commentators felt they had received effective support to take part, such as appropriate information, communication etc, although a few felt they could have benefited from more support.

"The advice guidance and support from the Scottish Government and from the facilitators (in advance of the session) was extremely helpful and appreciated."

"Mostly very good support but needed a little prompting so I could be clear about what the 'ask' was for me."

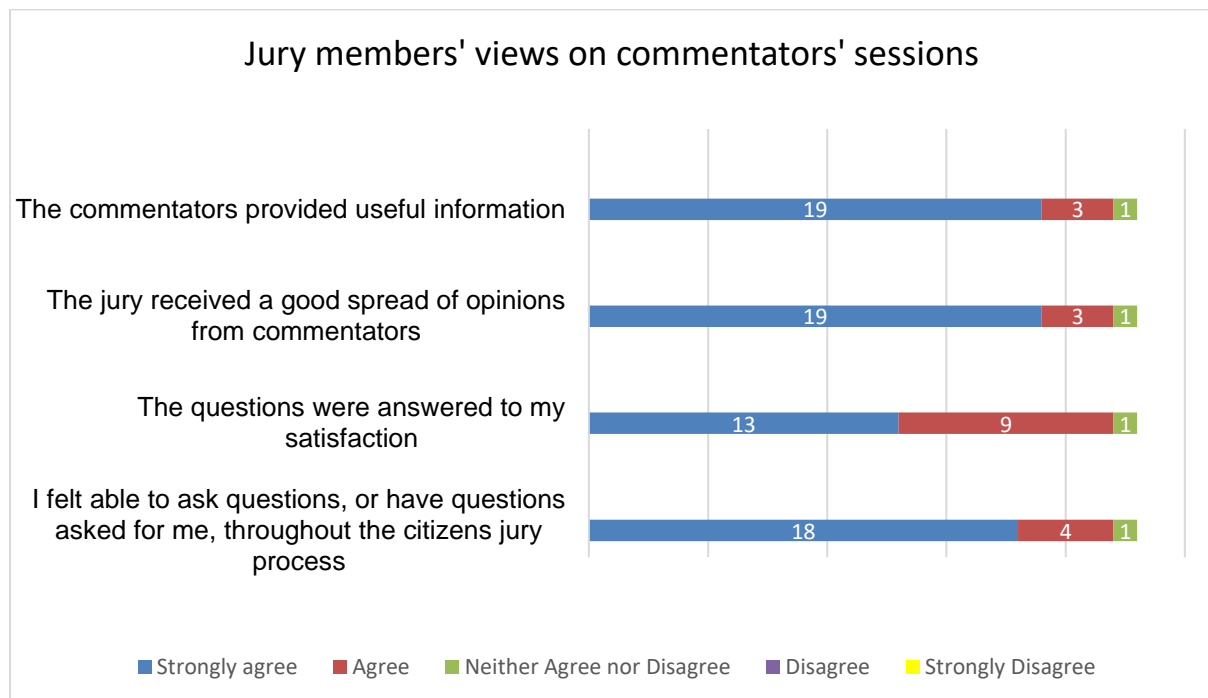
Commentators were asked approximately how long they spent on all aspects of the Citizens' Jury in their role as commentator – including preparation, travel and participation in the Jury. This obviously varied according to the travel aspect of each commentator's journey. The answers ranged from 6 hours to 21 hours, with the average time commentators spent on the Citizens' Jury around 12 hours. All commentators that responded felt that the amount of time spent on the Jury from their perspective was about right.

"I think it was right [amount of time] for the commentators' involvement. However, I think the commentators need to be included in a continuous cycle. Perhaps bring all commentators together for the final session and there is better information sharing between different individuals."

"It was a long time, but it was also a great experience for me and really good process - and well worth it."

Jury members were asked about their ability to ask questions of the commentators and the input from commentators. Twenty-two (22) of the 23 members that responded strongly agreed or agreed that:

- they were able to ask questions of the commentators, or have questions asked for them throughout the Jury process
- questions were answered by commentators to their satisfaction
- the Jury received a good spread of opinions from commentators, and
- the commentators provided useful information.



“The commentators were excellent with a wide variety of expertise and knowledge.”

“I felt the organisation was really good and gave us opportunity to move from this to another in short-bursts.”

Commentators were asked about the quality of interaction with Jury members and whether it went better than expected or less well than expected. Most of the commentators fed back that their interaction was positive.

“I was impressed by the richness of the discussion.”

“Overall, I was impressed with the knowledge and the participation of the jurors ... I felt the jurors were well researched, their questions relevant and they had a good grasp of the issues about which I spoke.”

“The jurors were great - super mix of backgrounds and views - people are so canny and good at picking up on things that really matter.”

All commentators who responded stated that they were free to explain their views on shared decision-making without any undue influence from facilitators or sponsors.

“They thought it was valuable to hear from an individual such as myself who is user-led of the health care services.”

“There was no pressure whatsoever to not give my own views.”

Commentators were asked if their participation in the Citizens’ Jury added to their knowledge on shared decision-making in any way. Eight out of the ten commentators that responded stated yes, one stated not sure and only one stated no.

“It helped me further appreciate the differing understandings and interpretations of shared decision-making by citizens, researchers and service-based providers.”

“Not lots in any theoretical sense, but it always helps to ground this in people's experience and there was plenty of that.”

When asked if anything else could have been done to improve their participation in the Jury as a commentator, half of those that responded said no (five), two said yes and three were not sure.

Areas for improvement included more time for commentators’ sessions; more support and thought for commentators to feel welcome and a part of the Jury process; and more focus on social care as well as healthcare.

“The quality of the interactions with jurors was very good but I think it would have been useful to have had more time.”

“My sense was that my connections across social work and social care agenda had been made late in the day – not designed in to the programme – this may have adversely affected the quality of interaction.”

“I was not reimbursed for travelling expenses, but was happy to bear that cost to be involved.”

5.4 Jury Recommendations Launch Event

On 6 February 2019, 13 representatives from the Citizens’ Jury presented their recommendations to the Chief Medical Officer and a range of health and social care stakeholders. 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 from health and social care, including the Jury commentators and Oversight Panel members.

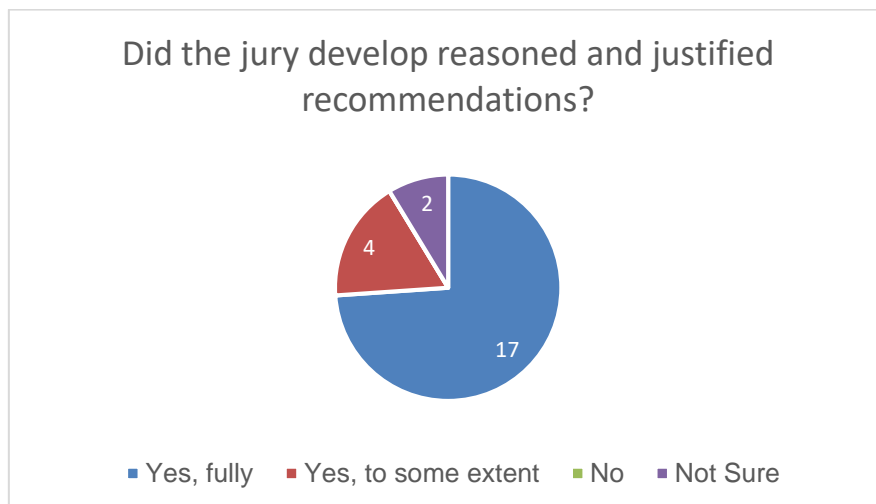
Feedback from the event was received from seven members of the Jury and 12 stakeholders. All rated the event as either very good or good. Stakeholders commented that it was valuable to hear about the process from the Jury members' perspective as well as meeting and discussing the issues with them. Jury members expressed positive comments about meeting the Chief Medical Officer and presenting their recommendations in person.



Citizens Jury Recommendations Launch Event, Dundee, 6 February 2019

5.5 Response to the Jury's recommendations

When asked whether the Jury developed reasoned and justified recommendations most Jury members felt that the recommendations were fully reasoned and justified.



Commentators were asked about their perception of the Citizens' Jury recommendations. Most of the comments to this question were largely positive. Commentators mainly found the Jury's recommendations thoughtful, positive and intelligent.

“Clear, common sense, if adequately actioned would move things considerably forward.”

“I think they vary in deliverability but they are thoughtful and intelligent. Given my own experience of the jurors that is not a surprise.”

“Broad but valuable and coincide in large part with views of those in the research and service areas that are involved in implementation. For example the emphasis on education and training is strong.”

Of the nine Jury members that responded to the evaluation after the Scottish Government published its response, all were positive about the Jury and its recommendations. Comments included how the Jury arrived at the recommendations in a democratic way:

“I’m pretty happy with the Citizens Jury’s recommendations. Everything was thoroughly discussed and those given most priority were arrived at in a fair and democratic manner.”

“They were decided by everyone and incorporated everyone’s idea and view.”

“The process was excellent bringing all Jury members together with their ideas to formulate the final recommendations. Personally I feel they make a lot of common sense and will be of benefit to the NHS as a whole.”

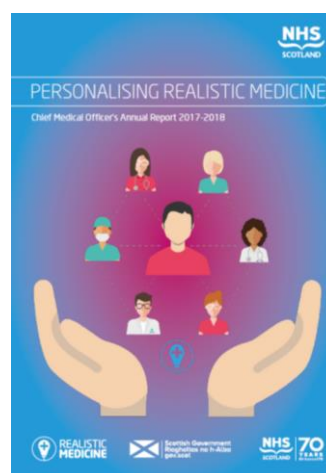
There were also comments relating to the diversity of the Jury.

“I really liked the broad and varied range of candidates chosen for the Jury. Young, old, those who are from affluent areas and those from less fortunate. I really liked the easy-going manner from the hosts and approach-fullness of guest speakers. It was casual and friendly with a great air of professionalism and we took the subject at hand very seriously.”

5.6 Chief Medical Officer and Scottish Government response to Citizens' Jury recommendations

The Chief Medical Officer, Catherine Calderwood, wrote about the impact of the Citizens' Jury in her annual report, *Personalising Realistic Medicine*, published in April 2019.

“The Jury has been a fascinating and most valuable exercise that has given us the opportunity to reflect on how we can get better at shared decision-making. I am aware that some have expressed concerns around whether the public are willing to be engaged on Realistic Medicine and even whether the public can be ‘realistic’. I do not believe that either concern is founded and this process has provided further evidence that, when provided with the information they need, the public can make practical and very sensible recommendations about how to provide better value care.”⁸



The Scottish Government produced its official response to the Citizens' Jury recommendations at the end of May 2019. The Scottish Government committed to take all of the recommendations forward with the exception of one, recommendation 9b, which recommended patients are able to continue to see the same medical professional throughout their care journey where possible. Whilst the Scottish Government is sympathetic towards this recommendation in principle, it highlights the practical difficulties of this in practice.

The Scottish Government's response to the recommendations includes details of work that will help to meet one or more of the recommendations which was already underway, as well as plans for new work to help to address gaps and enable the recommendations to be taken forward.

The Citizens' Jury recommendations therefore helped to reinforce and validate existing work on shared decision-making, as well as inform new work. The impact of the Jury's recommendation on the shared decision-making work programme is reported in section 5.

⁸Personalising Realistic medicine, CMO's Chief Medical Officer's Annual Report 2017-18, p15 <https://www.gov.scot/publications/personalising-realistic-medicine-chief-medical-officer-scotland-annual-report-2017-2018/>

5.7 Feedback on Scottish Government response from Jury members and commentators

Jury members and commentators were asked to what extent they agreed or disagreed that the Scottish Government's response appropriately addressed the Jury's recommendations. Of the nine Jury members that responded, four strongly agreed, four agreed and one member neither agreed nor disagreed. Comments from the Jury members included the following.

"It seems they took a lot of time reading over the suggestions and that they are willing to try and put a lot of the recommendations into practice."

"In terms of the Government's response everything was addressed in the report. Its success and commitment can't really be measured properly for a while as it will take time to implement and measure."

"It looks like the Government is on the face of it committing to the recommendations either in the future or through a variety of initiatives already in place. However it is my opinion that they will need to be closely monitored to ensure they deliver - actions speak louder than words."

Of the nine commentators that responded six agreed, one neither agreed nor disagreed, one disagreed and one strongly disagreed that the Scottish Government's response appropriately addressed the Jury's recommendations. Commentators' responses were mixed on this with some positive and some a bit more critical.

"Positive overall. The section on education and training appears to give the impression that all is well, but the reviews we, and others, have undertaken on national and local curricula suggest there remain big gaps in the shared decision-making skills training and assessment at both undergraduate and postgraduate levels. Current communication skills training remains variable but generally weak in the area of shared decision-making."

"Not especially helpful. The phrase 'Scottish Government is committed to taking this forward' followed by a lot of narrative only some of which is relevant and distinct lack of actually any measurable outcomes. Disappointing."

"This is a very positive response and this all clearly fits with a direction of travel for the Scottish Government."

5.8 Impact on the Citizens' Jury members

Jury members were asked their views on the following statements:

- Would you recommend to family and friends to participate in a Citizens' Jury?
- Do you think Citizens' Juries are a good way to involve the public in decisions about health and social care?

- Would you be willing to take part in another Jury on a different topic?

All 23 Jury members that answered the questions stated “Yes” to the three questions.

Referring to their experience of the Citizens’ Jury, some members’ comments included the following.

“This is a great experience. It’s not often you get the chance to speak up and get involved.”

“I have thoroughly enjoyed my time as a member and learnt about shared decision-making which will now allow me to challenge professionals.”

“I have really enjoyed the experience of sharing information and opinions with a diverse group of people. I feel enthusiastic about the topic discussed and hope that it will help.”

Jury members were also asked whether being on the Jury motivated them to do other things such as volunteering or community work, or perhaps something related to shared decision-making. Responses included the following.

“I have mentioned the Citizens’ Jury to family, friends and colleagues as I think it is a marvellous way to raise issues other than a petition as you have more time to be heard and decisions going forward are more thought about.”

“It’s definitely made me aware and gave me confidence to speak up and try and forge my own future. Being able to see a wide variety of society gave me an insight that I’m not totally isolated and my opinions matter. It’s helping me sort a police matter I should have had sorted years ago. Being part of Citizen’s Jury gave me confidence to get this addressed which I’ll forever be thankful for. I 100% enjoyed everything in the sessions and most confident the recommendations are of the highest quality. Thank you.”

“I enjoyed the process more than I thought I would and was impressed with how well it was organised and managed. It was nice to be involved in something positive that could benefit a lot of people. Yes I might be motivated to do something like this again.”

Tracking Jury members’ opinion towards shared decision-making

Jury members’ opinion towards shared decision-making was tracked at the beginning and end of each session by responding to a short questionnaire. The question asked:

“To what extent do you agree with the following statement: ‘Shared decision-making in healthcare is a good idea?’”

Jury members were asked to respond on a scale from Strongly agree to Strongly disagree. The results are summarised below by adding a score to the scale in the following way:

Strongly agree– 5, Agree– 4, Neither agree nor disagree– 3, disagree- 2, strongly disagree-1.

The table below summarises the results and shows that, whilst most were in agreement about the statement at the start, Jury members were more strongly in favour of the statement at the end of the Jury process.

Score	Session 1		Session2		Session 3	
	Start	End	Start	End	Start	End
5	10	19	15	18	21	19
4	13	5	9	6	2	2
3	1	0	0	0	0	0
2	0	0	0	0	0	0
1	0	0	0	0	0	0
Group score	105	115	111	114	113	103
Ave Score	4.4	4.8	4.6	4.8	4.9	4.9

5.9 Impact on shared decision-making work programme

The Scottish Government’s response to the Jury’s recommendations validated existing policies and work programmes on shared decision-making, as well as inform new work. New pieces of work which the Citizens’ Jury output has directly influenced include the following:

1 - Question Prompts⁹ (a set of question prompts which some NHS Boards are encouraging people to ask about their care): work has been commissioned to hold focus groups to discover how best these can be used. There are plans to use the output in a workshop with Realistic Medicine leads to further develop the national approach around the 5 questions (this relates to Jury recommendation 1).

2. Education and healthcare professionals. This was always a work stream within the Realistic Medicine delivery plan, but the validation from the Jury has accelerated this work. The Scottish Government has commissioned NHS National Education for

⁹ <https://realisticmedicine.scot/the-five-questions/>

Scotland to develop an educational module on shared decision-making and funded the appointment of a Realistic Medicine clinical lead specifically to develop an educational plan (Jury recommendation 2). This module was launched in December 2019.

3. Sharing the Jury report with stakeholders: The recommendations and Scottish Government response has been shared with NHS Board Chairs, who were asked by the Cabinet Secretary to describe how they are meeting, or plan to meet the recommendations at Board level. The report has also been shared widely within Scottish Government, with Realistic Medicine leads and Medical Directors in each NHS Board.

4. Value Improvement Fund¹⁰. The Value Improvement Fund is awarded annually to projects which support Realistic Medicine principles. The awards from the Value Improvement Fund in September of 2019 included two projects to progress recommendations from the Citizens' Jury:

- **National delivery of 'It's OK to ask'**

This proposal from NHS24 for a national 'OK to ask project' aims to help meet recommendation 1b from the Citizens Jury: "informing and educating patients of their right to ask questions of their health professionals by creating an accessible and effective digital first multichannel campaign".

- **5 questions in a secondary school**

This project from NHS Lanarkshire has been designed to introduce the concept of Realistic Medicine and the '5 questions' to school pupils. This project is running from November 2019 to January 2020 in St Margaret's High School, Airdrie. This project looks to support the Citizen's Jury recommendation 1c: "School visits to educate children about how to participate in shared decision-making by nurses or doctors".

¹⁰ <https://realisticmedicine.scot/value-improvement-fund/>

6 Conclusions

This evaluation concludes that the aims of this Citizens' Jury were largely met successfully. There is more evidence to support the successful implementation of the Jury process rather than the impact of the Jury, although it is recognised that it is early days in terms of implementing the recommendations.

As stated in section 3 of this report (Background), this was the first Citizens' Jury commissioned by the Scottish Government to consider a healthcare topic with the intention 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.

These two objectives have mainly been met.

The first objective was achieved by the Jury establishing its set of recommendations and the Scottish Government's response to these. It could be argued (as some commentators did) that the recommendations and response to them are mainly focused on health rather than social care, so further work may be needed on social care considerations for this objective to be fully achieved.

The second objective was to find out more about Citizens' Juries as an approach to citizen involvement and this was achieved by production of the first report on the Citizens' Jury and this evaluation report. It is also worth reflecting on the Chief Medical Officer's response about how valuable the Jury was and in particular her comment that:

"...when provided with the information they need, the public can make practical and very sensible recommendations about how to provide better value care."

As highlighted in section 4 of this report (Evaluation method and approach), the evaluation aimed to focus on the following key processes and outputs of the Jury and some brief conclusions are provided against each.

Recruitment and selection of Jury members – this was a success. There were many more applicants than expected, the recruitment and selection resulted in good diversity of Jury members and no Jury members dropped out of any of the sessions.

Facilitation and deliberation – was mainly regarded as very good by Jury members and commentators. One slight improvement could have been having more facilitators on a few occasions.

Size and length of the Jury – this seemed about right according to most Jury members, although some did say that the sessions were quite long and tiring. The size of the Jury could have been smaller, although there was an expectation that some members would drop out. A Jury of 18-20 members may have been more manageable for the amount of facilitators.

Expert input and role of the commentators – Jury members were very pleased with the commentators' input and commentators felt, on the whole, the process was well facilitated. One learning point is the importance of providing clear information and support to the commentators when they attend the event.

The recommendations – these were highly thought of by Jury members and commentators and, as highlighted above, the Chief Medical Officer felt the recommendations were a valuable contribution to improving shared decision-making. The Scottish Government response to the recommendations was on the whole well received although, as detailed above, a small number of commentators felt there was room for improvement. As it is still early days in the delivery of a work programme in response to the Jury recommendations, there is scope to address these points by the Scottish Government.

Overall, having commissioned and evaluated this Citizens' Jury, the Scottish Health Council concludes that a Citizens' Jury is a valuable tool to capture public involvement in health and social care in Scotland. It is an approach which can engage people and provide informed insight on a topic from a cross section of the public.

Sponsors of any future Citizens' Juries need to ensure that the Jury is suitably resourced, ensuring a robust approach to the process and the topic is carefully considered. Committing to responding to the Jury's recommendations from the outset, as the Scottish Government has in this case, is also an important facet of the Citizens' Jury approach. Given the resources a Citizens' Jury requires we suggest it is an approach to public involvement that lends itself more to a topic of regional or national interest.

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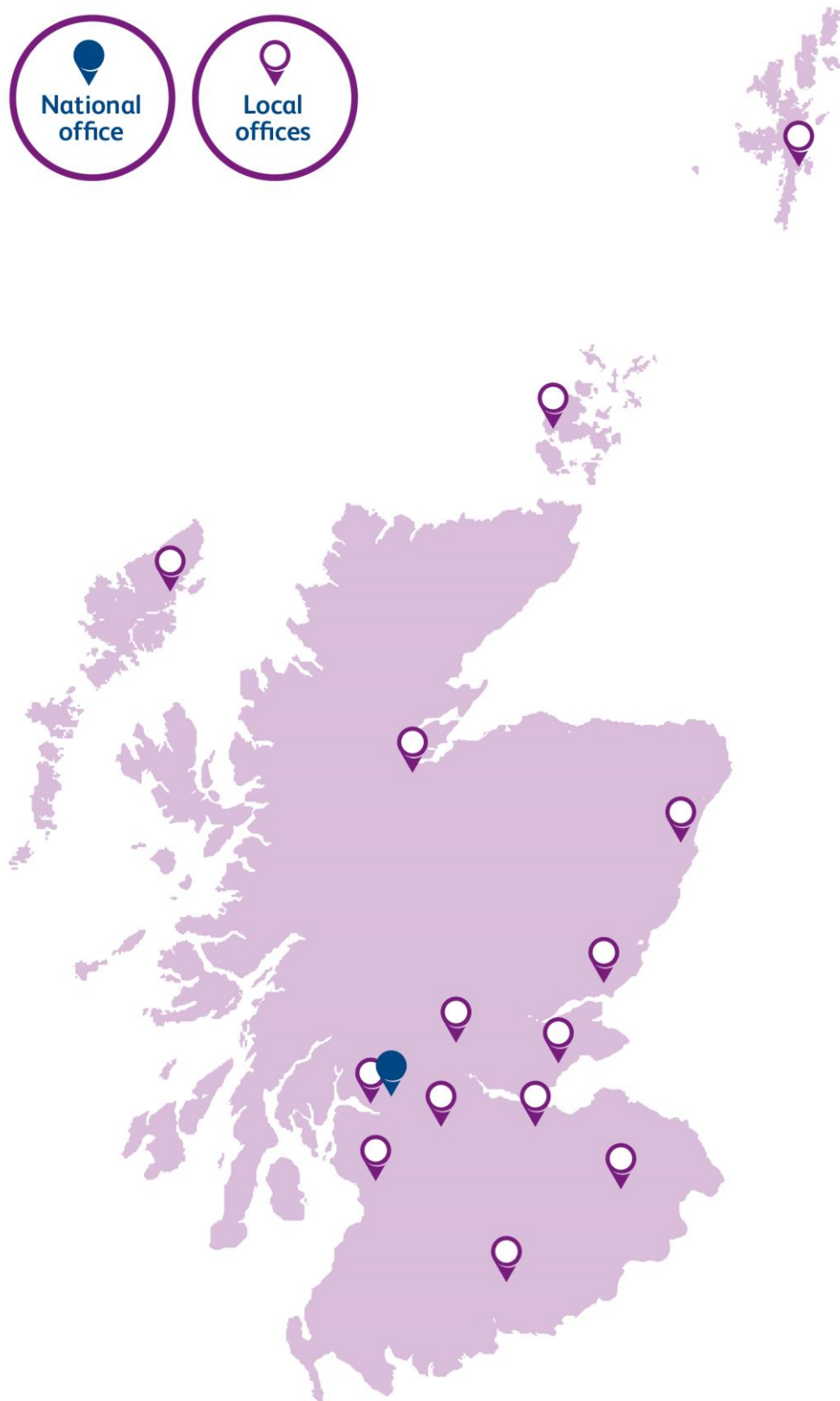
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