

Involving young people in planning and delivery of health and social care: Scoping a pan-Scotland collaborative approach

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Foreword

The Strengthening the Voices of Young People Project was a twelve month joint strategic initiative between the Scottish Health Council and Includem. The Scottish Health Council works in a variety of ways to improve the involvement of people and communities in health and social care services in Scotland. Includem is a specialist Scottish charity which supports vulnerable young people who are often excluded from mainstream services. Includem seconded an experienced member of staff to the Scottish Health Council for the duration of the project.

The Young Voices Project sought to promote the co-design of services between young people and key decision makers who influence their lives. It engaged with a wide range of organisations across Scotland to learn from their existing work to increase the inclusion of young peoples' voices.

The aims and objectives of the project included:

- exploring and developing innovative approaches to engaging with children and young people across Scotland, to ensure their voices are heard in line with the Our Voice Framework, and
- supporting the development of an evidence base for engaging children and young people in health and care, particularly those from excluded communities, and using this to promote good practice.

The project has worked collaboratively with stakeholders to hear the voices of young people, especially those who are often marginalised or excluded from genuine participation.

Based on early conversations with some stakeholders, we commissioned this scoping research that includes a rapid literature review and further stakeholder engagement to:

- map existing structures for young people's participation in planning and delivery of health and social care services in Scotland
- evidence whether there is a perceived 'gap' in engaging young people in the planning and delivery of these services
- identify the most appropriate structure/s for engagement in the planning and delivery of health and social care services
- consider opportunities for adding value and strengthening existing structures for hearing and acting on the voices of young people, and
- assess the appeal, viability, and feasibility of a pan-Scotland collaborative approach to young people's participation in the planning and delivery of health and social care services.

This scoping report forms part of a suite of reports that share other work we have undertaken as part of the Young Voices Project. The reports are available on the Scottish Health Council website.

We would like to offer our thanks to Dr Sheila Inglis and the late Mary Boyle of SMCI Associates for undertaking this piece of scoping work within a tight time schedule, working closely with Keir McKechnie, who led the Young Voices Project, and Wendy Brown, Social Researcher at the Scottish Health Council.

Further thanks go to all of the organisations who work with children and young people in Scotland, who directly took part in the interviews with the research team and who completed the online survey questionnaire.

We are especially grateful to all of the young people and the support staff who took part in this important piece of scoping work. We hope it will make a positive contribution to how health and social care services collaborate to ensure more effective participation of children and young people from wide and diverse backgrounds across Scotland.

Pam Whittle, CBE

Chair, the Scottish Health Council

1. Executive Summary

Introduction

This report provides the findings of a scoping exercise on the feasibility, desirability and rationale for the establishment of a pan-Scotland collaborative approach to young people's participation in the planning and delivery of responsive health and social care services. The work was undertaken by SMCI Associates (with Action for Sick Children Scotland) between January–March 2017.

Approach to the scoping work

This scoping exercise was undertaken by using a range of methods, including:

- stakeholder and key informant engagement with 19 organisations comprising a mix of young people's organisations, third sector organisations and health and social care organisations
- face-to-face and/or telephone interviews held with 21 stakeholders
- two surveys – an adult survey (190 respondents) and a young persons' survey (90 respondents)
- a literature review, and
- mapping of existing structures and approaches.

Feedback from surveys and interviews

Young people who responded to the survey think that it's a good idea to get young people's voices heard when people are planning how their health and social care is provided. They said that this is because:

- it's their **right** as the main stakeholders in health and social care service for young people, and
- it will lead to better services with better outcomes for young people.

More than half of young respondents (58%) who expressed an opinion consider that young voices are not being heard when health and social care services are being planned in Scotland. They said that this is because:

- they are not asked what they think when health and social care services are being planned, designed and delivered, and
- they feel ignored if they do speak up.

Fewer than half (43%) of the adults who responded to the survey consider that there are arrangements for involving young people in planning and/or delivery of health and social care services in Scotland. Survey respondents and interviewees noted that current policy and legislation – notably the Children and Young People (Scotland) Act 2014 – is driving the involvement of young people in planning, design and delivery of services. They also noted the significance of the United Nations

Convention on the Rights of the Child Article 12 – the right to say what they think when adults are making decisions that affect children, and for their opinions to be taken into account. Existing arrangements identified by survey respondents included the Scottish Youth Parliament, Scotland’s Commissioner for Children and Young People, Champions Boards for Care Experienced Young People, and Care Inspectorate Young Inspectors. Several very specific or local arrangements were also identified.

A quarter (25%) of respondents to the adult survey who expressed an opinion considered that current arrangements were not effective for involving young people in planning, design and delivery of health and social care services; with only 27% considering that current arrangements were effective. Champions Boards and Care Inspectorate inspections were identified as effective in involving young people; survey respondents and interviewees also noted that there was a lot going on to involve young people, and there were a lot of strengths. However, the main concern of survey respondents (26%) and interviewees is that current arrangements are seen as patchy, non-strategic and uncoordinated. They consider that there are significant inconsistencies in involving young people, both geographically and in relation to specific experiences or conditions – with some groups at risk of ‘involvement-fatigue’. Respondents also noted that organisations and practitioners often lack capacity to effectively involve young people in planning and delivery of services.

More than three quarters (79%) of the respondents to the adults’ survey who expressed an opinion said that the “development of a pan-Scotland collaborative approach to involving young people in planning and/or delivery of health and social care services would be welcome”; and 60% of respondents considered such a development would be feasible.

The main reason (28%) for welcoming a pan-Scotland approach was that it could lead to better services with better outcomes; 13% considered that it could help develop practitioner capacity and good practice; and 9% considered that it could help develop consistency and equality in service provision and involving young people. It would also be welcome in implementing Article 12 of the United Nations Convention on the Rights of the Child (5%); and because young people want it (4%).

Survey respondents and interviewees were cautiously optimistic that a pan-Scotland collaborative approach to involving young people in planning and/or delivery of health and social care services could be feasible, so long as it:

- is effectively resourced
- makes effective use of existing arrangements
- is young person led
- secures effective buy-in from all stakeholders, and
- has strong leadership and governance arrangements.

A key issue is that it's simply not known whether a pan-Scotland collaborative approach to involving young people in planning and/or delivery of health and social care services would be feasible (37%), with survey respondents noting that there is little or no evaluation of the impact of current arrangements to involve young people in planning, design and delivery of services.

Literature review

There is very little published evidence about which structures and processes work well in involving young people in the planning and delivery of health and social care services; and indeed very little published evidence that involving young people in planning and delivery of services makes any difference. Despite this, there is a strong view – supported by current policy and legislation – that it is a good thing to involve young people in planning and delivery of services. This view is informed by rights-based approaches, but also the belief that involving young people in planning and delivery will lead to better services, and better outcomes.

The literature shows that effectively involving young people in planning and delivering services is challenging, and requires considerable thought and effort – in particular to ensure that involvement is truly inclusive.

More than half of the papers identified addressed issues of power in involving young people in planning and delivery of services, stressing the importance of clarity over the limits of shared decision making and the need to develop ‘alternative’ collaborative approaches to effectively involve young people. The need for practitioners to be skilled in involving young people in planning and delivering services was similarly stressed, with skills in facilitation being particularly important. ‘Alternative’ collaborative approaches include involving young people in training staff – which may help to address power issues.

Existing structures and mechanisms

The scoping work included mapping existing structures for young people’s participation in planning and delivery of health and social care services in Scotland. This was informed by stakeholder interviews, and focused on information that was provided on organisations websites.

Mapped structures/organisations by focus	Number of structures	%
Children and young people focus but no health/social care focus	20	36%
Health/social care but no children and young person focus	10	18%
Looked After children and young people	8	15%
Health/social care relating to all children and young people	8	15%
Children and young people with cancer	2	4%
Children and young people with mental health issues	2	4%
Young carers	2	4%

Blind and visually impaired children and young people	1	2%
Children and young people with disabilities	1	2%
Deaf and hearing impaired children and young people	1	2%
Total	55	100%

Conclusions and recommendations

There is a cautious optimism that a pan-Scotland collaborative approach to involving young people in planning and/or delivery of health and social care services is both welcome and feasible, so long as it:

- is effectively resourced
- makes effective use of existing arrangements
- is young person led
- secures effective buy-in from all stakeholders, and
- has strong leadership and governance arrangements.

The main reason for welcoming a pan-Scotland approach was that it could:

- lead to better services with better outcomes
- help develop practitioner capacity and good practice, and
- help develop consistency and equality in service provision and involving young people.

There is no strong appetite for the establishment of a new Scottish Young Persons Health and Social Care Forum, essentially because there are many existing structures for involving young people. There is, however, scope for coordination of existing structures; with more than three quarters of people responding to the adults' survey saying that they would welcome the development of a pan-Scotland collaborative approach to involving young people in planning and/or delivery of health and social care services.

A key issue is that it's simply not known whether such an approach to involving young people would be feasible, with stakeholders noting that there is little or no evaluation of the impact of current arrangements to involve young people in planning, design and delivery of services. This was also a finding of the rapid literature review.

It is recommended that the Scottish Health Council, in line with its work to support the delivery of the Our Voice framework, explores further with stakeholders:

1. Their views on developing a pan-Scotland collaborative approach that:
 - a. is led by young people
 - b. builds on existing arrangements for involving young people
 - c. evaluates its impact.
2. How best to develop practitioner capacity and good practice in involving young people.

2. Introduction

This report provides the findings of a scoping exercise on the feasibility, desirability and rationale for the establishment of a pan-Scotland collaborative approach to young people's participation in the planning and delivery of responsive health and social care services. The work was undertaken by SMCI Associates (with Action for Sick Children Scotland) between January–March 2017.

The report sets out:

- background and context
- approach to the scoping work
- stakeholder perspectives on:
 - current arrangements and rationale for developing structures and mechanisms for involving young people in the planning and delivery of health and social care services
 - desirability and feasibility of a pan-Scotland collaborative approach to involving young people in planning and/or delivery of health and social care services
- evidence on best practice structures and mechanisms for involving young people in the planning and delivery of health and social care services
- existing structures and mechanisms in Scotland for involving young people in the planning and delivery of health and social care services, and
- conclusions and recommendations.

3. Background and context

The participation of children and young people in decision-making in Scotland is now widely accepted, supported by policy and legislation. This includes the Children and Young People (Scotland) Act 2014, which places a clear duty on public authorities to publish every three years “a report of what steps it has taken in that period to secure better or further effect within its areas of responsibility of the United Nations Convention on the Rights of the Child requirements” (Part 1, section 2).

Article 12 of the United Nations Convention on the Rights of the Child provides the right for children to say what they think when decisions are being taken that affect them, and that their opinions should be taken into account.

The Children and Young People (Scotland) Act 2014 also places a duty on local authorities and NHS Boards to “prepare a children’s services plan for the area of the local authority” (Part 3, section 8); and section 10 requires them to consult widely, including with organisations which “.. represent the interests of persons who use or are likely to use any children’s service or related service in the area of the local authority”. Scottish Government Statutory Guidance on Part 3 (Children’s Services Planning) of the Children and Young People (Scotland) Act 2014 provides that:

“When identifying relevant organisations to consult, local authorities and health boards may wish to give particular attention to how the views of children, young people and families (i.e. the users of “children’s services”) are obtained. Although not on the face of the Act, consulting with children and young people (including those from marginalised or vulnerable groups) and their families is good practice. Getting It Right For Every Child places the child’s views at the centre of planning and decision making and the United Nations Convention on the Rights of the Child requires national and local governments, as duty bearers, to respect, protect and fulfil children’s rights.” (para 91).

3.1 The Scottish Health Council

There is a growing emphasis on engaging and consulting with people and communities, recognising their expertise, opinion and perspective in multiple areas of health and social care development. The primary objective of the Scottish Health Council - which is part of Healthcare Improvement Scotland – is to improve how the NHS listens to the public, values their views and experiences and involves them in planning and developing responsive services. Working with stakeholders, the Scottish Health Council provides a range of advice, support and resources that helps NHS Boards develop more inclusive approaches to participation and deliver care that is person-centred.

The Scottish Health Council aim is to improve how the NHS:

- listens to you
- values your views and experiences
- respects you as an individual, and
- involves you in planning and developing health services.

3.2 The Our Voice Framework

The Scottish Health Council is responsible for delivering key aspects of the Our Voice framework. Our Voice is based on a vision where people who use health and care services, carers and the public will be enabled to engage purposefully with health and social care providers to continuously improve and transform services. Our Voice will be responsive to citizens, providing feedback on the impact of their engagement, or a demonstration of how their views have been considered.

Our Voice seeks to ensure that everyone has the opportunity to get involved and shape health and social care services, including young people. This scoping exercise will inform the delivery of the Our Voice vision for young people, and will help the Scottish Health Council to improve the range of ways in which young people can share their views and become involved in the planning and delivery of health and social care support services.

4. Purpose of the Scoping Work

The purpose of the scoping work commissioned by the Scottish Health Council and agreed with the research team was as follows¹:

“A scoping exercise of the feasibility, desirability and rationale for the establishment of a pan-Scotland collaborative approach to youth participation in the planning and delivery of responsive health and social care services.

Through stakeholder engagement, mapping existing structures and processes, and rapid literature review, the scoping work will:

- map existing structures for young people’s participation in planning and delivery of health and social care services in Scotland
- evidence whether there is a perceived ‘gap’ in engaging young people in the planning and delivery of these services
- identify the most appropriate structure/s for engagement in the planning and delivery of health and social care services
- consider opportunities for adding value and strengthening existing structures for hearing and acting on the voices of young people, and
- assess the appeal, viability, and feasibility of a pan-Scotland collaborative approach to young people’s participation in the planning and delivery of health and social care services”.

¹ Action note of meeting with the Scottish Health Council on 6 January 2017

5. Approach to the scoping work

The scoping work was designed to:

- engage stakeholders – young people and adult practitioners working with and for young people, and
- synthesise the evidence on:
 - best practice structures and mechanisms for involving young people in the planning and delivery of health and social care services (rapid literature review), and
 - existing structures and mechanisms in Scotland for involving young people in the planning and delivery of health and social care services (mapping work).

5.1 Stakeholder and key informant engagement

The research team worked closely with the Scottish Health Council to identify stakeholders and informants. Organisations which took part in the scoping work are listed in appendix A.

5.2 Stakeholder interviews

Face-to-face and/or telephone interviews were held with 21 stakeholders, see appendix B. See appendix C for interview topic guide.

5.3 Surveys

Two online surveys were conducted, one for adults (targeted to engagement/participation leads); and one for young people. In addition to the Scottish Health Council, three agencies contributed to the development of the survey for young people: Enable, Who Cares?, Scotland, and the Teenage Cancer Trust. The surveys were circulated to organisations representing young people and asked to circulate to their members and contacts. Respondents selected whether they completed the adult survey or the young person's survey.

The surveys were open for three weeks during March 2017, and headline findings were provided to the Scottish Health Council's "Transforming How We Engage with Young People in Scotland" event on 31 March 2017. At that event, an electronic poll was also conducted.

Respondents selected whether to complete the adult or the young persons' survey.

There were 190 responses to the adults' survey. Of the 55% (104) who provided details of the sector in which they work, 50% (52) were from the NHS, and 32% (33) from the third sector. Only 11% (11) respondents were from local authorities. Most (56%) of the 52 NHS respondents who provided detail of the NHS Board in which they were employed were from the south west of Scotland: NHS Lanarkshire

and NHS Greater Glasgow and Clyde. Lanarkshire was also well represented by local authority staff.

Forty adults said that they were happy for the Scottish Health Council to know that they had responded, and left their contact details.

Ninety people responded to the young people's survey, 14 (16%) of whom were adults. Four of the adults responding to the young people's survey said that they were professionals working with young people – responding on their behalf; and one adult respondent was responding on behalf of her son.

Most (44%) of the 43 respondents to the young people's survey who provided detail of where they live indicated they were from the south west of Scotland: Dumfries and Galloway (8), East Ayrshire (7) and Glasgow City (4).

See appendix E for details of response to both surveys.

5.4 Literature review

The scoping work included a 'rapid review'² of the literature. This took two approaches:

1. A rapid review of selected bibliographic databases.
2. A review of the grey literature³ identified through work to 'map' existing structures for young people/s participation in the planning and delivery of health and social care services in Scotland.

The review was designed to answer the following question:

What is reported to work well and is considered and/or evidenced to be best practice structures/mechanisms for involving young people in the planning and delivery of health and social care services in Scotland, UK and Europe?

See appendix F for search strategy.

5.5 Mapping existing structures and approaches

The scoping work included mapping existing structures for young people's participation in planning and delivery of health and social care services in Scotland. This was informed by stakeholder interviews, which informed the rapid literature review. It also involved web-based scanning of organisations websites.

See Appendix G for Mapping Summary.

² See, for example http://www.nccmt.ca/pubs/Methods_Synthesis1.pdf

³ Grey literature refers to documents that are not found through publishers or databases, such as organisation reports and conference reports. Such literature is not generally peer reviewed.

6. Stakeholder perspectives

6.1 Introduction

This section provides the outcomes of two online surveys, one for adults (targeted to practitioners); and one for young people. Respondents selected whether to complete the adult or the young persons' survey.

It also provides the outcomes of an electronic poll conducted during the Scottish Health Council's "Transforming How We Engage with Young People in Scotland" event. This event included both adults and young people.

This section also provides the outcomes of interviews with 21 adult stakeholders. Illustrative quotes from survey responses to open-ended questions and interviews are provided in italics.

A note on the analysis

Please note that response rate to each question varies, and that percentages relate to responses to the specific question.

The analysis of response to open-ended questions in the young people's survey is in terms of the number of respondents to that question, for example, 33 (37%) of the 89 young respondents who provided comments to the question 'Please tell us why you think that it IS a good idea to get young people's voices heard when people are planning how your health and social care is provided' indicated that it is their right as the main stakeholders – see section 5.2.1.

Analysis of responses to open-ended questions in the adults' survey is through analysis of responses to open-ended questions overall, as the specific question responses do not always answer the specific question. As such, percentages relate to percentage of the overall response to the survey i.e.190. This is because there are many more open-ended questions in the adult survey, with scope for overlap of response.

6.2 Young people's perspectives

Young people's perspectives were collated through an online survey. Significant efforts were made to engage young people in face-to-face activities, but the timescale of the scoping work (3 months) militated against this.

Ninety people responded to the young people's survey, 14 (16%) of whom were adults. Four of the adults responding to the young people's survey said that they were professionals working with young people – responding on their behalf; and one adult respondent was responding on behalf of her son.

Most (44%) of the 43 respondents to the young people’s survey who provided details of where they lived were from the south west of Scotland: Dumfries and Galloway (8), East Ayrshire (7) and Glasgow City (4).

6.2.1 A good idea to get young people’s voices heard in planning, design and delivery

The vast majority (97%) of young respondents who shared their opinion said that “it is a good idea to get young people’s voices heard when people are planning how your health and social care is provided”. No respondents said that it isn’t a good idea. See table 1.

Table 1: Young people’s survey: Is it a good idea to get young people’s voices heard when people are planning how your health and social care is provided?

Answer Options	Response	
	Count	%
Yes	76	97%
No	0	0%
Don’t know	2	3%
Total	78	100%

Young respondents suggested many reasons why it is a good idea to get their voices heard when people are planning how health and social care is provided. These included:

1. It is their right as the main stakeholders in health and social care services for young people (37% of 89 responses)

- “Young people are the future and are going to grow up with the social and health care so we should have a choice and idea of how it is managed.”
- “We should be listened to and our opinions taken into consideration. This means that the planning will focus more on what we want, would like to see and need.”
- “It is OUR health and social care; we should be involved as we know best.”
- “It will directly affect us and we deserve a say in important decisions that may have an impact on OUR bodies and the way we will have to live OUR lives.”
- “IT’S OUR FUTURE NOT OLD PEOPLE’S!!!!!!”
- “Because it affects us greatly, so surely we should have a say on what we want provided.”

2. It will lead to better services, with better outcomes (30% of 89 responses)

- “You can't provide a good service to someone if you don't know what they need.”
- “They are far more likely to engage with services and have positive outcomes and wellbeing if they are listened to and understood. Services are also more likely to become relevant and impactful for young people.”
- “Young people use health and social care services all the time. They are also innovative and creative and will challenge static, old fashioned ways of being/systematic barriers to change.”
- “If a service is aimed at young people, it is essential that the facilities and opportunities are targeted at the right people – therefore the best people to refer to on growth of a service should be done in collaboration with the demographic using the facilities.”
- “Young people are more likely to be able to explain their difficulties re access or information re the type of service requirements that suit them which could lead to improved health and care outcomes.”

6.2.2 Are young people’s voices already heard in planning, design and delivery in Scotland?

More than half of respondents (58%) who expressed an opinion considered that young people’s voices are not already heard when planning health and social care services in Scotland.

Twenty one percent (12) respondents who expressed an opinion thought that young people’s voices are heard; and 21% respondents (12) who expressed an opinion did not know whether young people’s voices were heard in planning health and social care services in Scotland. See table 2.

Table 2: Young people’s survey: Are young people’s voices already heard by people who are planning how your health and social care is provided?

Answer Options	Response	
	Count	%
Yes	12	21%
No	33	58%
Don't know	12	21%
Total	57	100%

Respondents to the young people’s survey said that young people are not being heard in planning health and social care services because:

1. Young people in Scotland are not asked what they think about the design and delivery of health and social care services (17 respondents: 19% (n89))

- “I’m currently working on my university dissertation, focusing on using Cool2Talk⁴, an online health intervention and its implementation .. in April 2017. After speaking to numerous young people through focus groups, one question was this, and they said no one ever speaks to them or acknowledges them or their problems, and they feel neglected by the health and social sector.”
- “I’ve been using NHS services (physiotherapy, occupational therapy, Child and Adolescent Mental Health Services and Community Mental Health Teams) for most of my life, but I’ve never been consulted by anyone on how I found my treatment or how I could improve it.”
- “Never in my lifetime have I been asked for my opinion in regards to my own health. Also in my time as a representative of young people [I] have complained numerous times about the lack of provisions to support young people being involved in service planning.”

2. Young people in Scotland feel ignored if they do speak up (13% of 89 responses)

- “Sometimes no matter what we say, we are often ignored or ridiculed.”
- “No one listens to what I want to happen with in my shared lives placement.”
- “If young people try and get [our] voices heard [we] are belittled and not listened to. The older people providing care for [us] think they know best and just go by the assumption that [we] are just complaining for the good of [our] own health not that [we] might have something of value to say that could help improve the quality of care for young people.”

Comments provided by those respondents (21%) who considered that young people are being heard in planning health and social care services indicate that being heard depends on specific local contexts – and usually specific individual practitioners:

- “Only by some professionals who take the time to listen and try to understand what we are saying.”

6.3 Adults’ perspectives

Adults’ perspectives were collated through an online survey, and interviews with 21 strategic stakeholders.

There were 190 responses to the adult’s survey. Of the 55% (104) who provided details of the sector in which they work, 50% (52) were from the NHS, and 32% (33) from the third sector. Only 11% (11) respondents were from local authorities.

Most (56%) NHS respondents were from the south west of Scotland: NHS Lanarkshire (18) and NHS Greater Glasgow and Clyde (11). Lanarkshire was also well represented by local authority staff.

⁴ <http://www.cool2talk.org/>

6.3.1 Current arrangements in Scotland for involving young people in planning, design and delivery of health and social care services

Almost half of the respondents (49%) to the adult survey did not know whether currently there were any arrangements in Scotland for involving young people in planning and/or delivery of health and social care services. 43% (82) considered that there were arrangements for involving young people; and only 8% considered that there were no arrangements. See table 3.

Table 3: Adult’s survey: At the moment are there any arrangements for involving young people in planning and/or delivery of health and social care services?

Answer Options	Response	
	Count	%
Yes	82	43%
No	15	8%
Don’t know	93	49%
Total	190	100%

Policy and Legislation featured in 45 (24% of 190 respondents) survey respondents’ comments about current arrangements:

- “Getting It Right For Every Child and the Children and Young People (Scotland) Act 2014 ask that the voices of children and young people are listened to and that authorities report back on those findings.”
- “Strategic Commissioning Plans across Scotland reflect the action to garner information on how people view health and social care and their integration which includes children and young people.”
- “Via Ready To Act⁵ and the whole ethos of person-centred care.”
- “Informing, Engaging and Consulting people in developing health and community care services Chief Executive Letter (4) 2010 ⁶ guidance says that people potentially affected by a change should be involved in consultation on that change.”

Interviewees also noted that legislation is increasingly driving the involvement of young people in planning, design and delivery:

⁵ Scottish Government (2016) Ready to Act - A transformational plan for Children and young people, their parents, carers and families who require support from allied health professionals (AHPs) <http://www.gov.scot/Publications/2016/01/1324>

⁶ http://www.sehd.scot.nhs.uk/mels/CEL2010_04.pdf

- “Recognition that Voices must be heard – United Nations Convention on the Rights of the Child Article 12. The Children and Young People (Scotland) Act 2014 has increased the potential for a stronger young people’s voice.”
- “There’s huge willingness and encouraging voices possibly due to the push from legislation. The Carers (Scotland) Act 2016 clearly states that there should be partnerships at local level which give the opportunity for young carers to be involved in health and social care agendas.”

Comments made by 19% (37, n190) survey respondents pointed to existing participation arrangements for young people, with the following being identified:

- “Scottish Children and Young People's Commissioner.”
- “Scottish Youth Parliament and the Youth Forums that feed in to this.”
- “Champions Boards for Care Experienced Young People.”
- “The Care Inspectorate involves young people in regulation as young inspection volunteers. They are also involved in the Involving People Group looking at policy and strategy. Young inspection volunteers are consulted with regularly.”
- “Action for Sick Children Scotland participation project.”
- “Royal College for Paediatrics and Child Health participation group.”
- “I believe that the Royal College of Psychiatrists in Scotland Child and Adolescent Faculty have had involvement from young people, and also the college nationally.”
- “I am aware that there are a number of national initiatives including young MSP and through school structures that allow for engagement and representation at a national level.”
- “The Teenagers and Young Adults Cancer Managed Service Network Youth advisory forum.”⁷
- “I believe young people are involved with the Mental Health Access Improvement Support Team (Mental Health Access Improvement Support Team) re CHILD AND ADOLESCENT MENTAL HEALTH SERVICES.”

Specific organisations were mentioned by 18 (9% n190) of survey respondents:

- Who Cares? Scotland (10 respondents)
- Young Scot (7 respondents)
- Action for Sick Children Scotland (3 respondents)
- PAMIS (Promoting a more inclusive society)⁸ (1 respondent)

Devices and tools were mentioned by 5 (3%, n190) survey respondents:

- Children with Exceptional Needs⁹ talking mats to collate young people's opinions.

⁷ <https://www.youngcancer.scot.nhs.uk/managed-service-network/working-groups/teenagers-and-young-adults>

⁸ <http://pamis.org.uk/>

⁹ <http://www.cen.scot.nhs.uk/>

- Ready steady go tool¹⁰.
- Care planning/ Management plans.
- Diaries of like and dislikes.

Additionally, several specific local/individual initiatives were mentioned by 14 (7%, n190) survey respondents, see appendix H for details.

6.3.2 Effectiveness of current arrangements in Scotland for involving young people in planning, design and delivery of health and social care services

The response to the question on the effectiveness of current arrangements in Scotland for involving young people in planning and/or delivery of health and social care services was low (27%). Nevertheless, almost half of those who expressed an opinion (48%) did not know whether current arrangements are effective (see table 4).

Of those who did respond to the questions (see tables 4 and 5), 59% considered that there are gaps in the current arrangements for involving children and young people; and 25% considered that current arrangements for involving young people in planning and/or delivery of health and social care services are not effective.

More than half of the participants (57%) at the Scottish Health Council’s “Transforming How We Engage with Young People in Scotland” event considered that young people are involved in the planning and delivery of health and social care services in Scotland “a bit”; with 38% saying that they are not involved – and only 5% considering that they are involved.

Table 4: Adults’ survey: Are the current arrangements in Scotland for involving young people in planning and/or delivery of health and social care services effective?

Answer Options	Response	
	Count	%
Yes	14	27%
No	13	25%
Don’t know	25	48%
Total	52	100%

¹⁰

<http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx>

Table 5: Adults’ survey: Are there any gaps in the current arrangements in Scotland for involving young people in planning and/or delivery of health and social care services?

Answer Options	Response	
	Count	%
Yes	86	59%
No	1	1%
Don’t know	58	40%
Total	145	100%

Survey respondents who considered that current arrangements for involving young people are effective specifically mentioned:

- Champions Boards for Care Experienced Young People
 - “Here in Highland Champions Board have implemented change in partnership with corporate parents so I believe that this is a very successful example of young people being involved and supporting planning that affects them.”
- Joint inspections of children’s services
 - “Young people have been involved in all Joint Inspections of Children's Services in Scotland since 2012 and are important members of the inspection team.”
- “Young people can engage through schools, voluntary organisations and there are additional care supported sectors including young carers and corporate parenting initiatives which will focus on care aspect of a young person’s life.”

Interviewees also commented that current arrangements for involving young people have “lots of strengths”:

- “There’s lots of strengths. Much more consultation goes on now that in the last 10 years or so. There are also many more opportunities for involvement. For example, a consultation event with young people changed a section of the Carers (Scotland) Bill. The proposal was that all children and young people had a child’s plan and that there would be no special arrangements made for young carers. At the consultation event the young people disagreed with this approach, found it patronising and made alternative proposals. The result was that provision for a

Young Carers Statement was included in the Act and which is quite separate from the child's plan. If consultation had focused only on professionals or organisations then it is unlikely that this change would have been made."

- "The inclusion agenda in schools is a real strength. The Rights/Respect initiative in schools is also strength."
- "The fact that the Scottish Health Council is engaging with the third sector as part of this scoping is a strength. A real willingness from organisations to listen to young people - maybe the mechanisms are not robust but the commitment is there."

One interviewee expressed concerns that good practice in involving children and young people may be "sidelined" as Integration Joint Boards are established:

- "There was some great practice in involving children and young people prior to the establishment of the Integration Joint Boards now I'm worried that children and young people will be sidelined by Integration Joint Boards because of the juggernaut of adult services."

Survey respondents (26%: 49, n190) and interviewees considered that current arrangements for involving young people in planning, design and delivery of health and social care services in Scotland are patchy, non-strategic and uncoordinated. Survey respondents' comments included:

- "Although there are duties on statutory bodies with responsibility for planning to consult with a wide range of relevant bodies, there is no explicit reference made to how children and young people should be involved. There needs to be much more of an explicit expectation set out with clear guidance on how this should be approached."
- "Integration has meant a very complex picture across Scotland with services to children being part of some Health and Social Care Partnerships and not others. The overall visibility of the needs of children and young people is a concern in recent reviews of strategic plans of Health and Social Care Partnerships and we still have more work to do articulating how their work links to Local Outcomes Improvement Plans and Children's Services Plans."
- "There is no framework involving NHS Boards or Health and Social Care Partnerships in a recognised structure for involving young people in service planning/delivery, though there have been some piecemeal initiatives."
- "Not at a consistent level country-wide. Involvement and consultation is too much in the gift of planners, rather than a duty recognised by them."
- "There are pockets of work where young people are engaged and involved in health and social care service planning but there appears to be a lack of consistent and structured approach to this across Scotland."

Interviewees' comments on current arrangements echoed those of the survey respondents:

- “Some examples of good practice but probably patchy.”
- “Current arrangements are not representative of all groups. Scotland has the intention but has not cracked it yet.”
- “There’s lots of activity on young people’s involvement – but maybe not focused on health and social care, but certainly linked. There’s lots happening in bubbles.”

Survey respondents (9%: of 190 responses) also noted that organisations and practitioners often lack capacity to effectively involve young people in planning, design and delivery of health and social care services in Scotland:

- “Approachability of health professionals is patchy and often not always engaging with young people.”
- “There needs to be more capacity building and ongoing support for participation of those in our communities - otherwise the policy and legislative framework will fail to live up to our collective aspiration of a dramatic shift in power, culture and ultimately improvements in the outcomes and experiences of local people.”
- “The barriers to participation are enormous - from lack of capacity/confidence to participate to unrealistic or demanding timeframes which make meaningful dialogue a challenge.”

Fifteen percent (28) of all open comments (n190) to the adult survey commented that there simply are no arrangements for involving young people in planning and/or delivery of health and social care services, with comments including:

- “No young person that I work with has ever been asked their opinion regarding planning of services.”
- “Working across Scotland for a large voluntary organisation I am unaware of any structural approaches to engaging young people in the planning of health services.”
- Existing arrangements generally focus on adults
 - “Seldom do you see young people on our public forums.”
 - “The Patient Partnership Forums tend to be adult focussed and are not always representative of children and young people.”
- But arrangements for involving adults are often ineffective or non-existent:
 - “I am sure there are gaps for young people but indeed for all people. Most plans are made by small groups of professionals in council and NHS buildings.”
 - “The first step would be to engage people of all ages and tell them what is planned and ask their views.”

Interviewees and survey respondents (5% of 190 responses) noted that there tends to be a reliance on specific groups of young people. Survey comments included:

- “I think the downfall is that we aren't always engaging with the right young people? Or those who are disengaged and would benefit from the ability to influence and implement change. Often the young people involved in this kind of work are already very engaged and confident. We need to reach a wider base of young people.”
- “They seem to lack consistency and often only ask young people who are already engaged and will use services. Better attempts at reaching those who are more at risk of poor health in later life is needed.”
- “Generally we ask those young people who are already engaged.”

Interviewees’ comments echoed those of survey respondents:

- “Another weakness in current arrangements is the concentration of networks in the central belt.”
- “Arrangements are not representative. There’s lots of groups out there but fall-back position is often to ask Scottish Youth Parliament, this is certainly not representative of all young people.”

Two interviewees considered the likelihood of ‘engagement-fatigue’ in some groups:

- “There’s a risk of over consultation because we are upping the game.”
- “It’s about how we engage and when, this has to be at a time when it suits the young person. Often professionals ask for engagement sessions during young person’s group time but it is **their** [the young person’s] time. In the case of young carers this is probably the only respite they get.”

Survey respondents noted gaps in involving young people in relation to specific services

- Mental health (7 respondents)
- Long term conditions (3 respondents)
- Learning difficulties (3 respondents)
- Transition into adult services (2 respondents)
- Physical disabilities (1 respondent)
- Housing (1 respondent)

6.3.3 A pan-Scotland collaborative approach?

More than three quarters (79%) of the respondents to the adults’ survey who answered the question (121) said that the “development of a pan-Scotland collaborative approach to involving young people in planning and/or delivery of health and social care services would be welcome”; and 59% (78) respondents considered such a development would be feasible. See tables 6 and 7.

Very few survey respondents (4%) considered that such a development was neither welcome nor feasible.

More than one third (37%) of survey respondents who expressed an opinion did not know whether the development of pan-Scotland collaborative approach to involving young people in planning and/or delivery of health and social care services would be feasible; and 17% (21) respondents did not know whether such a development would be welcome. See tables 6 and 7.

The overwhelming majority (99%) of participants at the Scottish Health Council’s “Transforming How We Engage with Young People in Scotland” event considered that young people need to be better involved in planning and delivery of health and social care in Scotland.

Table 6: Adult survey: Would the development of a pan-Scotland collaborative approach to involving young people in planning and/or delivery of health and social care services be welcome?

Answer Options	Response	
	Count	%
Yes	95	79%
No	5	4%
Don't know	21	17%
Total	121	100%

Table 7: Adult survey: Would the development of a pan-Scotland collaborative approach to involving young people in planning and/or delivery of health and social care services be feasible?

Answer Options	Response	
	Count	%
Yes	78	59%
No	5	4%
Don't know	48	37%
Total	131	100%

A pan-Scotland collaborative approach would be welcome

Five percent (9) of all survey respondents (n190) said that a pan-Scotland approach to involving young people in planning and/or delivery of health and social care services would be welcome because it would be about more effectively implementing Article 12 of the United Nations Convention on the Rights of the Child (United Nations Convention on the Rights of the Child:

- “Sorry, bit of a no brainer. The United Nations Convention on the Rights of the Child Article 12 states that children and young people have a right to be involved in making the decisions that affect them.”

Four percent (8) survey respondents said that a pan-Scotland would be welcome because young people want it:

- “In our work and with our partners we can see there is an appetite from children and young people to be more involved in decision making, especially decisions that have a direct impact on their lives.”
- “Young people are interested in being involved. However current methods of involving young people can learn a lot from the way young people were involved in the Scottish Care Leavers covenant.”

Thirteen percent (25) survey respondents considered that a pan-Scotland approach would be welcome because it could develop practitioner capacity and good practice:

- “Support the workforce – ensuring their understanding of the importance of this approach and then the practical steps to putting this into practice. This will need appropriate time and resourcing.”
- By developing practice standards
 - “This would be able to set the strategy direction and could develop best practice models for engaging people at the more local level.”
 - “A collaborative approach that could provide a clear framework based in best practice and offer examples of standardised as well as new or unique approaches rather than a prescriptive, one size fits all approach.”
- By sharing good practice
 - “Establishing good practice, rather than bitty practice. Learning from each other etc.”
 - “It would be useful to share experiences across organisations and allow young people to experience a wider view of provision of services for them.”

More than one quarter (28%) survey respondents considered that a pan-Scotland approach could lead to better services with better outcomes:

- “Involving young people in the services which affect them should form the fundamental basis when planning or delivering services, thus ensuring services provide what is needed and what will make a positive difference for young people.”
- “It is essential that we involve young people in this work so that our services reflect their needs and helps develop services which are user friendly and relevant.”

Nine percent (17) respondents considered that a pan-Scotland approach could help to develop consistency and equality:

- In service provision (9)
 - “To ensure all children and young people are given the same opportunities and access regardless of where they live.”
- In involving young people in planning, design and delivery of health and social care services (8)
 - “Working together we could achieve more than working in isolation, those who work with young people are keen to include them in consultations but often resources are slim, a collaborative approach would involve combining resources and working together to have all voices heard, not just the confident.”
 - Across areas, the extent to which young people are involved in health and social care planning/delivery will vary. A pan-Scotland approach will allow for equity and ensure young people from all areas have a voice.”

A pan-Scotland collaborative approach would be feasible

Survey respondents were optimistic, but slightly less certain that a pan-Scotland collaborative approach would be feasible: 79% (95) of those who expressed an opinion would welcome it, but only 60% (78) considered that it would be feasible. All 21 people interviewed considered that a pan-Scotland collaborative approach to involving young people in planning and/or delivery of health and social care services would be welcome – if various conditions were met.

This cautious optimism was articulated around the following areas.

Resourcing

More than one fifth (22%: 41) survey respondents made comments relating to resourcing:

- Time costs:
 - “More time would be needed to plan service change and provision and we do not have the numbers in the workforce to provide this at present.”
- Funding to support young people’s participation:
 - “Money would need to be allocated to support young people to participate. e.g. carer payment/hotel overnight stay, depending on location, special changing spaces etc.”
- Prioritisation:
 - “Not given priority by regional or national governing bodies or by health and social care resource allocation managers.”
- Ring-fenced funding:
 - “Need ring-fenced resources for this activity and clear lines of accountability for those responsible for outcomes and communication.”
- Partnership approaches:
 - “If a clear, coordinated and collaborative approach was embedded across Scotland that was included within funded agreements for voluntary

organisations, it would include partnership work and capacity building approaches across Scotland to increase the feasibility and means for more meaningful participation for young people in delivering, or shaping the delivery of services.”

All 21 interviewees reflected on the need to effectively resource a pan-Scotland collaborative approach to involving young people – both in terms of financial resource, and the development of staff capacity and skills.

- “It needs to be resourced, not massively: they need to harness and enhance the capacity of organisations already doing this, to do more.”
- “It would need cost neutral funding: get the Directors of Planning and Child Health Commissioners on board.”
- “There’s a need to train the professionals: Scottish Social Services Council has a role, National Education Services has a role. Probably not statutory training, but about the practitioners hearing stories from young people about what makes a difference, and then reflecting on the implications for their own practice. But we need to be careful not to disempower staff – we need to work from their strengths.”

Two interviewees expressed concerns that such an approach would not be cost effective:

- “It is probably feasible but time, money and resources would need to be put into a national approach. Is this cost effective?”
- “I can see it being a bit of a white elephant - and not cost effective.”

Making effective use of existing arrangements

Twenty nine percent (56) of survey respondents considered that the development of a pan-Scotland approach would only be feasible if it made use of existing arrangements:

- Children And Young People (Scotland) Act 2014:
 - “The Children And Young People (Scotland) Act 2014 ensures a framework of procedures and professionals are in place to support collaboration.”
- Community Planning arrangements:
 - “We have many mechanisms for community planning and service planning.”
 - “We already have the 'national standards for community engagement'.”
- Child Health Commissioners:
 - “Utilise the children’s commissioners groups to agree governance arrangements.”
- Commissioner for Children and Young People:

- “Work has already been undertaken by the Commissioner for Children and Young People about principles of good participation.”
- Scottish Youth Parliament:
 - “This is an ideal opportunity to harness the scope and reach of the Scottish Youth Parliament to ensure that from the start, the initiative is embedded within schools, youth groups and communities of interest.”
- Champions Boards:
 - “This approach is already developing for care experienced young people in the context of Champions Boards and Health and Social Care Partnerships.”
- Schools:
 - “Young people can have their say during high school lessons that are directed at personal development or through a forum where there is a selection of pupils from each year as representatives. In primary again a pupil’s style council could represent their peers. In nursery the smiley faces can tell us if they think they are getting the health service they deserve.”
- National third sector organisations:
 - “It would be important to include the national youth organisations in this process at an early point. Professional youth work methods will be crucial in enabling meaningful outcomes.”
 - “Working with local and national voluntary organisations would enable statutory services to be able to work with young people who engage in local services.”
- Local/specific arrangements, see appendix H for details.

One comment articulated a concern implicit in comments made by 56 (29%) survey respondents regarding the need to make effective use of existing arrangements:

- “There are existing structures and arrangements in place to engage and consult with young people on a number of issues not just health and social care and I am not convinced that we need additional arrangements.”

All 21 people interviewed also considered that the development of a pan-Scotland approach would only be feasible if it made use of existing arrangements:

- “It would need to be integrated with Community Planning, and Children’s Services Planning.”
- “It needs to build on, and connect with what’s already there. It would need to have the full recognition of the Integration Joint Boards.”
- “It should contribute to the ways that universal services involve children and young people in planning e.g. through school structures, corporate parenting, community engagement. The expertise in involving children and young people is in schools, community learning and development – not generally in health.”
- “The Scottish Children’s Parliament and the Scottish Youth Parliament provide opportunities for young people to take part in reporting structures.”

There was a strong view from interviews that the establishment of a new structure would not be the way forward:

- “We don’t need a new structure – that would be very resource intensive.”
- “There are other structures in place locally and nationally that do a good job.”
- “The intention behind this is great, but avoid duplication and use what we have got in place already.”
- “There are too many structures and resources out there – there’s a need for rationalisation. All the specific groups want their say – but there’s a need for a strategic overview.”
- “There’s a need to coordinate existing activity – perhaps through two or three national gatherings each year.”

Being young person led

Thirteen percent (24) survey respondents considered that the development of a pan-Scotland approach to involving young people in planning, design and delivery of health and social care services could only be feasible if it was young person led:

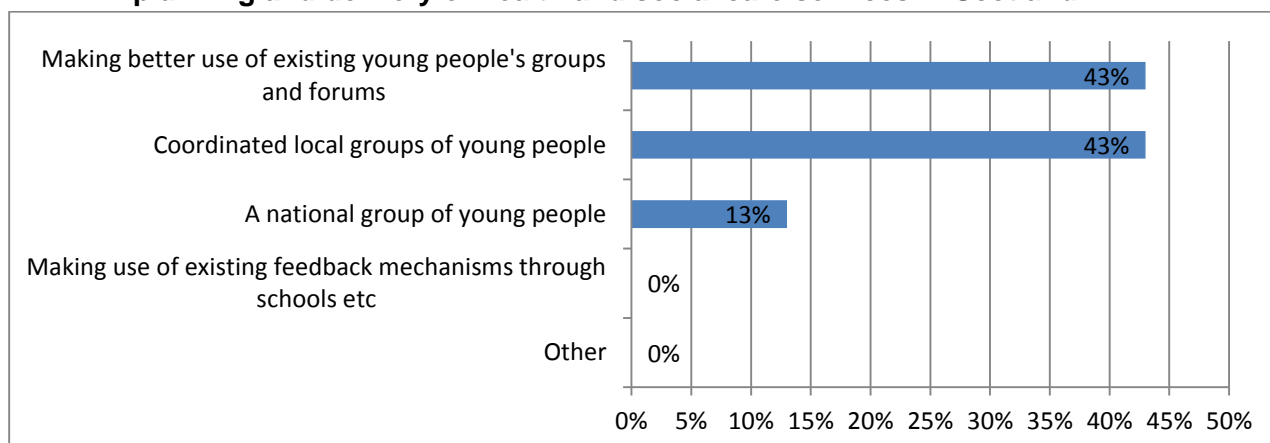
- “It will be essential that young people are viewed as equal and able partners in the collaboration.”
- “Place the young people at the centre with real authority, while effectively supporting them to fully realise their potential and the potential of the approach.”
- “They need to be included equally from the very beginning, not an add on towards the end.”

Half of the people interviewed consider that a pan-Scotland approach should be young person led:

- “There’s a real appetite from young people to get more involved in health and social care planning. But we need an effective support mechanism so that they have skills, knowledge and experiences so that they come informed to collaboration and participation, they take empowered leadership, and are strategically engaged. Young people need to be at the heart. They need to be involved from the start, so that services are more fit for purpose in the long run.”

When asked what needs to be done to better involve young people in planning and delivery of health and social care services in Scotland, participants at the Scottish Health Council’s “Transforming How We Engage with Young People in Scotland” event were offered a choice of one of five options. ‘Making use of existing young people’s groups and forums’ and ‘coordinated local groups of young people’ were the most popular options (each with 43%). Only 13% participants selected ‘a national group of young people’. See figure 1.

Figure 1: Electronic poll: What needs to be done to better involve young people in planning and delivery of health and social care services in Scotland?



Lack of evidence

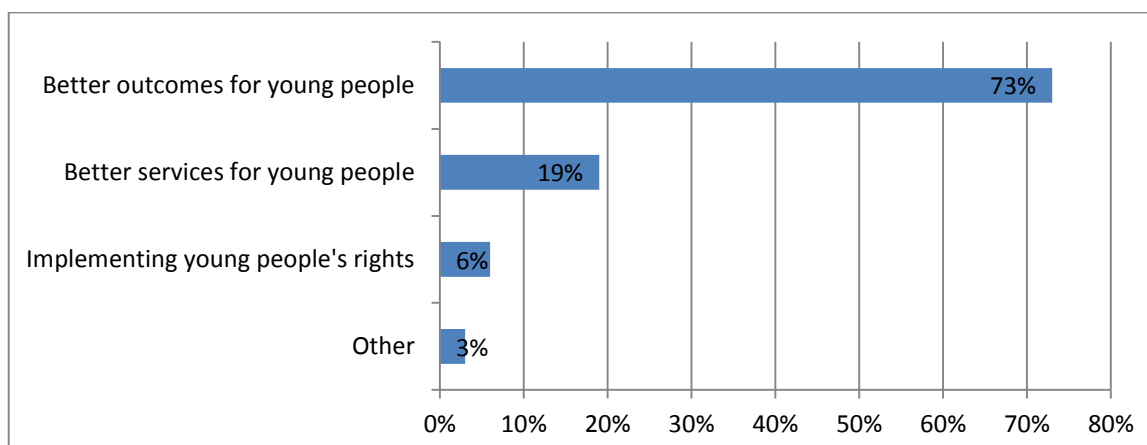
A key issue is that survey respondents simply don't know whether a pan-Scotland collaborative approach to involving young people in planning and/or delivery of health and social care services would be welcome (17%) or feasible (37%), see tables 6 and 7.

Survey respondents' comments indicate that there is little or no impact evaluation.

- "I certainly found a young person speaker at a recent conference had a huge effect on her audience but have no way of knowing how much impact that kind of activity has when it comes to actually planning services."
- "I have not seen any report that specifically demonstrates the positive outcomes from any such forum - just heard that they take place."

When asked what difference would involving young people in planning and delivery of health and social care services in Scotland make, participants at the Scottish Health Council's "Transforming How We Engage with Young People in Scotland" event were offered a choice of one of four options. Almost three quarters (73%) selected 'better outcomes for young people'; with 19% selecting 'better services for young people'; and only 6% selecting 'implementing young people's rights'. See figure 2. The challenge for what happens next will be to evidence the difference made.

Figure 2: Electronic poll: What difference would involving young people in planning and delivery of health and social care services in Scotland make?



Ensuring a pan-Scotland collaborative approach

In addition to ensuring that a pan-Scotland approach to involving young people in planning and/or delivery of health and social care services is effectively resourced, uses existing arrangements, and is young person led, survey respondents stressed that such an approach should be inclusive/get buy in (6%)

- “By ensuring that there is true co-production with local and national third sector organisation that represent young people, and not just lip service being paid.”
- “Representation from all Health and Social Care Partnerships in Scotland, ensuring in particular that the voices of more vulnerable young people are heard.”
- “Chief Executive buy-in from all agencies.”
- “Support from Child Health Commissioners and Advocacy services.”

Some survey respondents (4%) considered that legislation – or at least clear government direction – would be necessary to ensure the implementation of a pan-Scotland approach to involving young people in planning and/or delivery of health and social care services.

- “I feel it would be need to be written into legislation which would mean that management levels would have to support and enforce it within services.”
- “The actions undertaken by the Scottish Government, Parliamentary Committees, local elected members, inspection agencies and others as part of the range of post-legislative scrutiny would need to be clearly set out so colleagues are aware there will be follow up and feedback on their planning practice.”

Interviewees also stressed the need to secure buy-in:

- “It would need to have recognition as having a valued part to play: commissioners of services and the Scottish Government need to value the group and its input.”

Some survey respondents (7%) made suggestions about the structure of a pan-Scotland approach:

- National leadership, governance and guidance
 - “National initiative with strong guidance on roll-out, and continued support and follow up.”
- A hub and spoke approach
 - “National forum bringing together young people from across Scotland, and a local group within each health board. A local rep from each health board attend national forum so there is a link/consistency there.”
- Co-production
 - “Using a relation-leadership approach - cooperation, coproduction and a visible leader who truly believes in the capacity and value of all those contributing – a team approach.”
- Evaluation
 - “It is important to ensure there is supported and meaningful engagement and not just a ‘tick box’ exercise. Engagement needs to go beyond the consultation stage and there should be ‘progress reports’ built into the process, along the lines of the PDCA cycle (Plan, Do, Check, Act). The young people themselves should be the arbiters of whether the delivery of health and social care services have improved.”
 - “A linked-up formal network across Scotland with equal and appropriate proportional representation providing published results/outcomes of work as part of routine assessments.”

Interviewees also had suggestions about structure and nature of a pan-Scotland approach:

- Leadership, governance and guidance
 - “Guidelines on governance would be crucial.”
 - “It could strengthen existing provision but there are serious questions about the feasibility. Who would run the group and be responsible? There would have to be a very clear remit. There would need to be a host organisation. It would need people who have expertise in working with young people.”
- A hub and spoke approach
 - “It could use the hub and spoke model of local engagement feeding into a national group.”
- Co-production
 - “It would need to be a co-production.”

Interviewees also reflected on the role of the Scottish Health Council:

- It could play a key role in staff development, training and the promotion of good practice

- “The Scottish Health Council could set the aspiration for what young people’s participation in health and social care planning looks like; it could encourage all health and social services to do it. Maybe it has a role to play in engaging the more unusual suspects e.g. by providing examples of good practice in innovative citizen engagement. The Scottish Health Council could set the conditions for young people’s involvement, e.g. the necessary staff skills for co-production and co-design with young people. Lots of other agencies have the same ambition to get young people involved in health and social care planning, so maybe the Scottish Health Council could be a ‘bridge’?”
- “The Scottish Health Council could showcase good practice to inspire others, e.g. through an annual conference. Perhaps like the Healthcare Improvement Scotland What Matters to You campaign 2016¹¹.”
- “I have reservations about the Scottish Health Council setting up a new structure – there’s a danger of missing the richness of what is already being done. The Scottish Health Council could do structural work, e.g. making sure that the Integration Joint Boards take account of the views of children and young people.”

Two interviewees considered that there may be a conflict of interest for the Scottish Health Council in leading the development of a pan-Scotland collaborative approach to involving young people in planning, design and delivery of health and social care services:

- “I’m anxious that the health world is dominated by provider interests: the Scottish Health Council has this exciting opportunity to represent children and young people, but it’s a bit too close to provider interests, and health service providers tend to boil children and young people down to their conditions.”
- “If the ambition is to develop a vibrant and sector-leading approach to involving children and young people in planning and delivery, then I’d love to see the Scottish Health Council taking a break away from being a provider-led agency.”

6.3.4 Where there is 'a will there is a way' ...

Survey respondents were generally optimistic about the possibility of establishing a pan-Scotland collaborative approach to involving young people in planning and/or delivery of health and social care services – where there is a will to do so:

- “With the will to achieve, nothing is impossible. It is mostly about leadership driving forward the initiative with committed and passionate teams who have a clear focus on results.”
- “If there is a will to do this across Scotland then there are people ‘out there’ with the necessary skills who will be able to put it into practice.”

¹¹

http://www.healthcareimprovementscotland.org/news_and_events/news/news_what_matters_to_you.aspx
<http://www.whatmatterstoyou.scot/>

Some interviewees were similarly optimistic – but cautious:

- “There is a willingness at the moment but in that willingness and desire to move forward there is often a lack of appreciation of the details of structures and mechanisms that need to be in place prior to any national group being set up.”
- “It’s a good idea but needs much thought.”

7. Literature review

The search of published literature resulted in only 14 relevant papers. This paucity is noted by nine of the papers reviewed [1, 2, 3, 4, 6, 9, 13, 14] – despite four of these being literature reviews [1, 4, 7, 9]. Authors particularly note the urgent need for robust evaluation of the efficacy and impacts of processes and structures designed to involve young people – there is very little published evidence that involving young people in planning and delivery of services makes any difference. Ruth Sinclair [13] noted in 2004:

“For many, children’s participation is a value or rights-based principle much like democracy, not something that has to be justified by evidence or which needs to ‘prove’ that it works. This, however, does not diminish the need for monitoring or evaluation as part of a learning culture — how do we ensure the widest representation of children; what processes, in which situations, do children find most meaningful; and what approaches help to bring about sustainable change – answers to questions such as these can help children and adults alike to achieve their objectives from any participation activity. And indeed developing an evaluative framework can help in clarifying those aims and objectives.”

7.1 Young people could make a difference

Authors note that young people value the chance to participate in the development of health and social care services [3], and that through participation they feel valued and respected [2,3]. Cheetham et al (2013)[2] references evidence that young people avoid using services not designed for them and that they believe are not respectful; and Jourdan et al (2016) [7] comment that research indicates that involving young people effectively in decisions about the design and implementation of interventions is critical for their effectiveness.

Tisdall & Davies (2004) [14] assert that:

“.. children and young people possess a range of influential resources: for example, they possess information and knowledge that policy makers require; they have strategic importance for policy makers who want to be seen to be including children and young people in decision-making processes and media producers who want to include them in programmes; they can mobilise into groups; and they can develop financial resources and staff (usually in partnership with adults or adult organisations).”

These resources could be used to make a significant difference to health and social care services; indeed Cavet & Sloper (2004) [1] also consider that:

“.. more effective, responsive services are likely to be developed as a result of listening to children and young people.”

7.2 Power issues need to be addressed

Seven papers addressed issues of power in involving young people in planning and delivery of services [3, 5, 6, 8, 11, 13, 14].

Gunn (2008) [6] asserts that the context in which participation takes place is a “crucial element in its success”. He considers that bureaucratic organisations with traditional hierarchies may face difficulties when initiating and sustaining participation, if stakeholders do not appreciate what type of power they have and how it can best be used to promote the voice of young people in policy making. He points to Social Care Institute for Excellence evidence that user involvement can be used as “technology of legitimisation” by sustaining management and government authority by appearing to be democratic, but without allowing “undesirable” policy shifts for public services. Percy-Smith (2007) [11] also notes research that indicates that organisational issues can undermine the participation of young people through, for example, inflexible bureaucratic structures which are not conducive to facilitating participation; and suggests that organisations should build cultures of participation to support the involvement of young people in service improvement.

Authors note the need for service providers to work in partnership with young people [3, 5, 11]; however, they also note that partnership implies that decision-making power is shared equally, whilst in reality this is often not feasible. Consequently, it is essential that the objectives and boundaries of young people’s involvement in decision making are very clear from the start [3].

Coad et al (2008) [2] stress that participation is multi-dimensional, and set out four key dimensions for understanding participation:

- The level of active participation: this varies, and is often seen in terms of the degrees of power sharing between adults and children. Coad et al (2008) [2] note that Roger Hart’s (1997) ‘ladder of participation’ is often used to describe the degree to which children are in control of the process. They suggest that different levels may be appropriate for different tasks as part of an activity, project or organisation.
- The focus of the decision making in which children may be involved; in particular whether decisions are public (i.e. relating to public services, and relevant to young people as a group); or private (i.e. within the family context or between individuals).
- The nature of participation activity: Coad et al (2008) [3] point to a wide range of processes and activities: one-off consultation exercises or longer term consultation processes such as young people’s forums or advisory groups; on-going involvement in the governance of institutions such as youth councils or young people sitting on boards; and young people-led organisations.
- The children and young people involved. Children and young people are a very diverse group, who are not only different in their personal circumstances (age, sex, ethnicity, culture, disability, social and economic circumstances) but also

in terms of their changing interests and capacities as they grow older. Coad et al (2008 [3]) stress that what is appropriate for one group may not suit another, and that it is necessary to design forms of dialogue and engagement that start from the position of the child, whatever their age or ability.

Coad et al stress that:

“.. the first imperative for any participation activity is clarity about its purpose. Why are we doing it? What are we seeking to achieve, short term and long term? What is in it for children? Only when the purpose of the participation is clear can adults be honest with themselves and with children about what can be offered in terms of power sharing and a realistic assessment of the likelihood of the project or activity effecting change.”

7.3 Effectively involving young people requires effort and skill

The evidence shows that effectively involving young people in planning and delivery services is challenging, and requires considerable thought and effort [1,2,3,14] – in particular to ensure that involvement is truly inclusive [2, 14]. Cavet & Sloper (2004) [1] point to evidence that it's necessary to use “ingenuity and skill” to effectively engage young people.

The available evidence suggests that adults need significant skills to effectively involve young people in service planning and delivery [1, 2, 3, 5, 9, 10, 11, 13].

Percy-Smith (2007) [11] suggests that people working to involve young people need to “bring young people and professionals together in a process of dialogue, learning and reflection”. He proposes that such an approach can bridge the “policy learning gap” between professional assumptions about young people’s health needs and the reality of young people’s own health concerns. His research:

“.. challenged health professionals to reflect on their own assumptions and practices in response to the complex health concerns of young people and the need to connect more effectively with the real lives of young people in research and policy development. The collaborative action enquiry approach used models an ‘alternative’ and arguably more effective approach to policy learning involving young people... The comments from professional participants and young people bear testimony to the potential contribution this approach can make to policy innovation and young people’s agency as partners in that process. Whether this happens depends on the commitment of adult professionals.”

Murray’s (2012) [10] analysis of the Disabled Children and Young Peoples Participation Project in one Health and Social Services Board area in Northern Ireland showed that skilled adult facilitators played an essential role in ensuring the success of the project:

“From an early stage in the project, it was important to create partnerships with Children’s Services Planning and with other statutory and voluntary agencies. This encourages policy makers and service providers to be accountable for listening to and acting on the recommendations of the young people. As facilitator I had to negotiate opportunities for young people to share their views with professionals who were willing to accept a power balance.”

She reports that the young people involved in the project have named these people ‘Champions’, and quotes one young person: ‘It is our experience that without the Champions we as young people would be powerless’.

Murray (2010) [10] stresses that:

“Good facilitation is perhaps one of the most important factors enabling the decision makers to engage with the young people and vice versa. It was necessary to enhance the young people’s ability to participate and communicate while encouraging a change in behaviours of those professionals such as respecting the young people’s views and not being overly sensitive to their criticisms. Moreover, the young people need to be informed about the structures of statutory policy making and key aspects of service delivery such as budgeting. This must be done using a medium best suited to the individual’s learning, sensory and communication needs.”

She reports that the project facilitated young people to train staff in the agencies which wish to consult with them, noting that this “encouraged a power balance between professionals and young people”.

The research of Franklin et al (2016) [5] explores how to develop the involvement of young people in social work training through social media. They worked with young service users to identify and review social media used by young service users to share experience and communicate knowledge. They found fewer social media resources than anticipated, and identified a need to develop new sustainable ways of enabling young people to have a voice.

7.4 Examples

The literature review provided four examples of involving young people in the planning and delivery of health and social care, which could be helpful to the development of a pan-Scotland collaborative approach. These examples are summarised below.

7.4.1 The Department of Health's You're Welcome initiative

The 'You're Welcome: Quality Criteria for Young People Friendly Health Services'¹² were developed by the Department of Health as part of a wider programme of work to raise the profile of young people's health in England, recognising that all young people are entitled to receive appropriate healthcare wherever they access it. The criteria outline principles that help health services to become young people friendly, and are based on examples of effective practice working with people under 20 years. The 'You're Welcome' quality criteria cover ten areas, including monitoring and evaluation, and involvement of young people. Implementation of the 'You're Welcome' quality criteria by health service providers is assessed through self-review¹³.

The Department of Health is currently (2017) working with Public Health England and NHS England to review the 'You're Welcome' accreditation process and to refresh the standards.

Cheetham et al (2013) [2] report on the outcomes of a regional conference which reviewed the implementation of the 'You're Welcome' initiative in North East England. Delegates suggested that 'You're Welcome' provided an opportunity to shape health services in response to young people's needs. Young people were trained and supported to be involved in visits to assess and verify health service providers self-review of the implementation of the 'You're Welcome' quality criteria. They reported that they have seen changes in healthcare services as a result of their participation, including changes in staff attitudes and the environment, and clearer explanations about confidentiality.

Cheetham et al (2013) [2] reports that Newcastle Upon Tyne Hospitals NHS Foundation Trust employees have seen improvement in structures, policies and decision making as well as innovative responses to the concerns raised by young people as a consequence of the 'You're Welcome' initiative.

7.4.2 The Disabled Children and Young Peoples Participation Project

Murray 2012 [10] reports on the Disabled Children and Young Peoples Participation Project . This was established by Barnardo's (Northern Ireland) in 2002 to explore ways of involving children and young people with disabilities in decision-making processes within Children's Services Planning of one Health and Social Services Board. The project was funded by the Board.

The project aims to facilitate the involvement of disabled children and young people aged 5–25 years with a range of physical, learning and sensory impairments in high

¹² <https://www.gov.uk/government/publications/quality-criteria-for-young-people-friendly-health-services>

¹³ <https://www.gov.uk/government/publications/self-review-tool-for-quality-criteria-for-young-people-friendly-health-services>

level, strategic Children's Services Planning, underpinned by the promotion of advocacy for individuals. The young people chose to call the group '6th Sense', with Murray 2012 [11] quoting one young participant: "We see ourselves as the eyes and ears of Children's Services Planning and the voice of children and young people with disabilities."

Young people are involved in every element of decision making within the project with an emphasis on ensuring that their participation in the project is fun. The project strives to be user led and enables young people to make their own choices about issues such as what information they wish to share, at what level they wish to participate, when they wish to participate, in which format they wish to be involved and what support they need to enable them to participate.

Murray (2012) [11] noted that it was recognised from the outset that the involvement of children and young people with disabilities would be time-consuming and required knowledge of disability issues and skills in engaging with individuals who had learning and communication difficulties. She stresses the importance of strategic and structured processes and trusting relationships:

"Our experience has highlighted that group advocacy by disabled young people must be built on a strategic and structured process such as regular meetings with one another and shared activities that develop their confidence and skills. While the method and level of participation is person-centred, the individual has the benefit of trusting relationships with their peers, facilitators and the professionals with whom they come into contact."

Murray (2012) [11] also stresses that the involvement of children and young people with disabilities needs to happen at strategic levels – and that requires funding:

"advocates in 6th Sense believe that while local advocacy is vital, the difficulties often lie in regional policies. They recognise the need to research issues, attend the project to learn skills and maintain transparent partnerships with professionals at all levels. They need to be informed and to inform policy makers at regional and national levels about what works well and to gain an understanding of government structures as well as prioritising within health and social care structures. The involvement of disabled children and young people in high level strategic planning can only happen if there is commitment to funding, which can create such environments as is Disabled Children and Young Peoples Participation Project."

7.4.3 The University Hospitals Coventry and Warwickshire's Youth Council

Coad et al (2008) [3] reflect on how an acute hospital trust established a Youth Council comprising 17 young people aged 11–18 years to improve children's service delivery in one NHS trust in the UK.

Recruitment procedures for this Youth Council aimed to be as inclusive as possible so as to ensure wide representation. Flyers, inviting those interested in forming a dedicated youth council for the local hospital trust, were sent out to all secondary schools in Coventry and surrounding areas. The flyer was also distributed in key areas of the trust's hospitals and on the children's ward and children's outpatient clinics. An open, all welcome recruitment event took place, which resulted in 20 young people attending the first meeting of the Youth Council. Agenda items for the first meeting included terms of reference, preferred format of meetings, times (monthly at 5pm after school/college) and venues. Subsequently there was an election for a Chair and Vice Chair, whose roles included setting the agenda in negotiation with the Patient and Public Involvement Facilitator and facilitating discussion.

Coad et al (2008)[3] note that there was a concern that many of the young people who might volunteer for a Youth Council would not be representative of the general population of young people as a whole; however, they found that membership when they were writing (2008) included "a range of young people of different ages, gender and ethnicity so whilst this concern was raised in reality the group are a rich, broad subsection of the local population."

In March 2007, when the Youth Council had been running for 18 months, it was decided to hold an evaluation workshop with members. Coad et al (2008) [3] report that the results of the evaluation workshop highlight that:

".. for young people's involvement to have a real impact they need to have meaningful opportunities to be involved in all phases of service development as well as being given the chance to evaluate any changes. Involving children and young people in service development is not about them doing it all themselves or even always taking the lead. Rather, it is about children and young people being given the opportunity to be involved meaningfully, as it suits them. This may involve them taking the lead, but it may also mean engaging in a process initiated by adults."

Coad et al (2008) [3] suggest that to bring about real benefits for all children and young people:

"an organisational shift is required in changing attitudes about participation, that is away from 'bolt on consultation' to valuing and developing person-centred models. This requires:

1. Creating a climate for participation where all children and young people feel welcome and valued
2. Using flexible and creative approaches relevant and appropriate for individual and groups of children and young people

3. Understanding the different mechanisms for involving children and young people in both the operation and the strategic development of an organisation, as well as in individual decision-making processes
4. Provide training opportunities for both practitioners and children and young people to develop the necessary skills, knowledge and experience
5. Build in reward mechanisms including feedback and evaluation.”

7.4.4 Royal College of Paediatrics and Child Health

The Royal College of Paediatrics and Child Health 2010 [12] Guide to the Participation of Children and Young People in Health Services suggests the following guidelines, echoing much of the literature reviewed above:

- Participation is defined as the process by which individuals and/or groups of individuals can influence the decision-making process and bring about change.
- Participation involves a continuum from involvement of individual young people in decisions affecting their daily life to the engagement of large groups of young people in making strategic decisions about the use of substantial healthcare resources.
- Children and young people’s right to participate in matters affecting their lives is laid out in the United Nations Convention on the Rights of the Child, a legally binding International convention.
- Participation of children, young people and their families in the design and development of services is government health policy.
- There are different degrees of children and young people’s participation and it is important to be aware of the pitfalls of non-participation such as tokenism, manipulation and decoration.
- The research evidence base for children and young people’s participation is limited. Future research efforts should concentrate on important health outcomes and consider the cost effectiveness of different methods of participation. Consideration should be given to how interventions such as participation impact on health inequality.
- Participation has the potential to reduce health inequalities; however this requires an understanding of existing power imbalances, barriers affecting the involvement of children and young people from diverse backgrounds and a range of experience, and an invested commitment to address the inequalities.
- The ethos, culture and environment in which children and young people participate should be safe, age-appropriate and accessible for children and young people with a range of abilities.
- Safeguarding children and young people, respecting their confidentiality and ensuring their wellbeing at all times is paramount to the success of any participation initiative and strategy.
- There are a number of key steps in planning a participation initiative. Children and young people should be involved in the planning. Youth workers have skills and expertise in facilitating the meaningful participation of children and young people.
- Service leaders should develop a culture of participation within their organisation.

- The participation of children and young people should be evaluated systematically and the outcomes shared with key stakeholders. The contribution that children and young people make should be valued and any successes celebrated.
- Children and young people can participate in many different ways, including commissioning services, designing the built healthcare environment, recruiting and selecting staff, governance of health services and developing healthcare research.
- There are many different methods by which children and young people can participate in health services including questionnaires and surveys, focus and advisory groups, interactive media, youth councils and forums or as mystery shoppers, young inspectors and young researchers.
- The participation of children and young people contributes to the quality of health services for children and young people, it improves the health of children and young people and it's fun!

7.5 References

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8. Mapping existing structures and mechanisms

The scoping work included mapping existing structures for young people's participation in planning and delivery of health and social care services in Scotland. This was informed by stakeholder interviews, and focused on information that was provided on organisations' websites.

The mapping included the following.

- National structures/organisations. There is a multitude of local level initiatives; however mapping these was beyond the scope of this work.
- Structures/organisations with a focus on children and young people.
- Structures/organisations with a focus on health and/or social care.

The mapping did not include the Scottish Health Council.

Fifty-five structures/approaches were identified; 71% (39) in Scotland; 27% (15) with a UK-wide remit; and one specific to England – the NHS England Youth Forum. Most (58%) were led by third sector organisations; and almost one fifth (18%) were set up by government.

Thirty-six percent (20) had a children and young people focus, but not a health and/or social care focus; and 18% (10) had a health and/or social care focus but not a children and young people focus.

Eight (15%) structures/organisations dealt with health and/or social care relevant to all children and young people. Almost one third (31%) of structures/organisations had a specific focus, with 8 working with and/or for Looked After children and young people. See table 1.

Forty-five percent (25) of structures/organisations had no clear mechanism or approach for involving young people in their organisational structure: these had a focus on professionals/practitioners working with and for children and young people.

Fifty-five percent (30) had structures or approaches for involving young people, 18 (33%) with a health and social care focus. Three of these are no longer active, leaving fifteen existing national structures/organisations which involve young people in health and social care planning and/or delivery. Six of these structures/organisations are UK wide¹⁴, and nine are specific to Scotland¹⁵.

¹⁴ Arthritis Care, Association for Young People's Health, INVOLVE: National Young People's Mental Health Advisory Group, RCPCH, The Mental Health Foundation, Young Health Movement

¹⁵ Action for Sick Children Scotland, British Sign Language Youth National Advisory Group, Care Inspectorate, Carers Trust Scotland, Children's Hearings Scotland, Enable, Haggieye, Includem, Who Cares? Scotland

There are nine organisations/structures which involve young people more generally: six in Scotland¹⁶; and three UK wide¹⁷.

It must be noted that the mapping provides a snapshot of the situation in March 2017: it is not definitive. Furthermore, the approach to involving young people was summarised by the researchers from review of the organisation's website only. It is entirely possible that some of the organisations which – from their website – did not appear to have clear structure or approach for involving young people in their organisational structure, may actually have such an approach.

Table 8: Mapped structures/organisations by focus

	#	%
Children and young people focus but no health/social care focus	20	36%
Health/social care but no children and young person focus	10	18%
Looked After children and young people	8	15%
Health/social care relating to all children and young people	8	15%
Children and young people with cancer	2	4%
Children and young people with mental health issues	2	4%
Young carers	2	4%
Blind & visually impaired children and young people	1	2%
Children and young people with disabilities	1	2%
Deaf and hearing impaired children and young people	1	2%
	55	100%

¹⁶ Article 12 in Scotland, Children and Young People's Commissioner Scotland, Scottish Youth Parliament, STUC Youth Committee, Young Scot, Youth Scotland

¹⁷ British Youth Council, Fixers, UK Youth Parliament

9. Conclusions and recommendations

There is a cautious optimism that a pan-Scotland collaborative approach to involving young people in planning and/or delivery of health and social care services is both welcome and feasible, so long as it:

- is effectively resourced
- makes effective use of existing arrangements
- is young person led
- secures effective buy-in from all stakeholders, and
- has strong leadership and governance arrangements

The main reason for welcoming a pan-Scotland approach was that it could:

- lead to better services with better outcomes
- help develop practitioner capacity and good practice, and
- help develop consistency and equality in service provision and involving young people.

There is no strong appetite for the establishment of a new Scottish Young Persons Health and Social Care Forum, essentially because there are many existing structures for involving young people: this scoping work identified 15 national structures for involving young people in health and/or social care: nine specific to Scotland; six UK wide. In addition, nine national structures for involving young people more generally were identified, six in Scotland and three UK wide.

There is, however, scope for coordination of existing structures; with more than three quarters of people responding to the adults' survey saying that they would welcome the development of a pan-Scotland collaborative approach to involving young people in planning and/or delivery of health and social care services.

A key issue is that it's simply not known whether a pan-Scotland collaborative approach to involving young people in planning and/or delivery of health and social care services would be feasible, with stakeholders noting that there is little or no evaluation of the impact of current arrangements to involve young people in planning, design and delivery of services.

This was also a finding of the rapid literature review.

There is very little published evidence about which structures and processes work well in involving young people in the planning and delivery of health and social care services; and indeed very little published evidence that involving young people in planning and delivery of services makes any difference.

The published evidence shows that effectively involving young people in planning and delivering services is challenging, and requires considerable thought and effort – in particular to ensure that involvement is truly inclusive. It stressed the need for practitioners to be skilled in involving young people in planning and delivering services, with skills in facilitation being particularly important.

9.1 Recommendations

This scoping work has successfully engaged more than 300 people – including 90 young people – in considering the possibility of a pan-Scotland collaborative approach to involving young people in planning and/or delivery of health and social care services. This has generated considerable discussion, further developed through the Scottish Health Council’s “Transforming How We Engage with Young People in Scotland” event.

It is recommended that the Scottish Health Council, in line with its work to support the delivery of the Our Voice framework, does the following.

- 1 Makes use of the interest created through the scoping work to explore further with stakeholders their views on developing a pan-Scotland collaborative approach that:
 - a. is led by young people
 - b. builds on existing arrangements for involving young people, and
 - c. evaluates its impact.
- 2 Explores with stakeholders how best to develop practitioner capacity and good practice in involving young people.

Appendix A: Engagement in the scoping work

Table 9: Agencies engaged in the scoping work

Organisation	Nature of organisation	Interview	Snowballed young people's survey
CELCIS	Academic		
Centre for Youth and Criminal Justice	Academic		
Health and Social Care Alliance Scotland	Agency membership		
Voluntary Health Scotland	Agency membership		
Care Inspectorate	Care Inspectorate	Y	
SSSC	Regulator	Y	
Children in Scotland	CYP Agency membership	Y	
The Scottish Children's Services Coalition	CYP Agency membership		
Together: Scottish Alliance for Children's Rights	CYP Agency membership	Y	Y
Article 12	CYP Representative	N/A	
CYPCS	CYP Representative	Y	
Scottish Youth Parliament	CYP Representative	Y	Y
STUC Youth Committee	CYP Representative		
Teenage cancer trust	CYP Representative	Y	
Who Cares? Scotland	CYP Representative	Y	Y
Young / Carers Trust	CYP Representative	Y	Y
Young Scot	CYP Representative	Y	Y
High Life Highland	Local 3rd sector provider		Y (after email)
SSSC	Regulator	Y	
RCPCH	Royal College	Y	Y
Scottish Government	Scottish government	Y	Y (building Safer Communities Team) (after email)
Children and Young People's Health Support Group	Scottish government		
Children's Hearings Scotland	Service provider	Y	
Scottish Children's Reporter Administration	Service provider		
Child Health Commissioners Scotland	Service Provider	Y	
Paediatric Nurse Managers	Service Provider	Y	

HMYOI Polmont	Service provider		
Includem	Service provider	Y	
Managed Clinical Network for Cancer	Service provider	Y	
NSPCC	Service provider		
Quarriers	Service provider		
Children 1st	Service provider		
Barnardo's	Service provider		
Chest Heart and Stroke Scotland	Service user representative		
Enable	Service user representative	Y	
SAMH	Service user representative	N/A	
Scottish Human Rights Commission	Service user representative		

In interviews, six agencies offered to 'snowball' the young people's survey by placing it on their websites, in newsletters, Twitter feeds etc. Following the first email with information about the scoping work and the survey questionnaires, two identified agencies (see table 1), and following additional agencies offered to 'snowball' the young people's survey:

- NHS Health Scotland
- NHS Western Isles
- Glasgow Council for Voluntary Services: Everyone's Children
<http://www.gcvvs.org.uk/our-projects/everyones-children/>
- NHS Greater Glasgow & Clyde in partnership with third sector agencies: Youth Health Service <http://www.yhs-ng.co.uk/>
- Highland Council: www.Hi-Hope.org Information and Opportunities for Young People in the Highlands

Appendix B: Interviewees

Judith Tait	Service Manager – Strategic Scrutiny for Children’s and Criminal Justice	Care Inspectorate
Karen Martin	Mental Health Development Coordinator	Carers Trust
Sally Egan	Child Health Commissioner	Child Health commissioners Scotland
Tam Baillie	Children and Young People's Commissioner	Children and Young People's Commissioner Scotland
Jackie Brock	Chief Executive Officer	Children in Scotland
Boyd McAdam	National Convenor and Chief Executive	Children’s Hearings Scotland
Christine Mullen	National Training Officer	Children’s Hearings Scotland
Jean McDonald	Campaign and Policy Manager	ENABLE
Kayleigh Thorpe	Youth Services Manager	ENABLE
Angela Morgan	Chief Executive Officer	Includem
Tracy Davis	National Network Manager	Managed Service Network for Children and Young people with Cancer
Jean Davies	Clinical Nurse Manager, Paediatric Services	NHS Ayrshire and Arran
Emma Sparrow	UK lead for Participation (including Scotland)	Royal College of Paediatrics and Child Health
Pamela Fotheringham	Learning and Development Adviser, Qualification and Standards Team	Scottish Social Services Council
Louise Morgan	Coordinator	Scottish Young Carers Services Alliance
Ben McKendrick	Chief Executive Officer	Scottish Youth Parliament
Louise Watt	National lead for Teenagers and YP with Cancer	Teenage Cancer Trust
Juliet Harris	Director	Together: Scottish Alliance for Children's Rights
Denny Ford	Engagement & Involvement Manager	Who Cares? Scotland
Ray McLean	Development and Participation Officer	Who Cares? Scotland
Lisa Murphy	Co-design Manager	Young Scot

Appendix C: Interview topic guide

Interview/Focus Group Topic Guide

1. Introduction
2. What are the current structures/mechanisms in your organisation which facilitate the involvement of young people in planning and/or delivery of health and social care services?
3. Is your organisation involved in other structures/mechanisms which facilitate the involvement of young people in planning and/or delivery of health and social care services?
4. What are your views about the current arrangements in Scotland for involving young people in planning and/or delivery of health and social care services?
5. What are the strengths and weaknesses of the current arrangements in Scotland for involving young people in planning and/or delivery of health and social care services?
6. Would the development of a pan-Scotland collaborative approach to involving young people in planning and/or delivery of health and social care services:
 - a. Be feasible?
 - b. Be welcome?
7. What would be the impacts on your organisation of the development of a pan-Scotland collaborative approach to involving young people in planning and/or delivery of health and social care services?
8. How could a truly collaborative pan-Scotland approach to involving young people in planning and/or delivery of health and social care services be ensured?
9. Any other comments

Appendix D: Survey questionnaires

Adult Survey

1 - At the moment are there any arrangements in Scotland for involving young people in planning and/or delivery of health and social care services?

Yes No Don't know

2 - Please describe any arrangements in Scotland that you know about for involving young people in planning and/or delivery of health and social care services?

3 - Are the current arrangements in Scotland for involving young people in planning and/or delivery of health and social care services EFFECTIVE?

Yes No Don't know

4 - Please tell us why you think that the current arrangements in Scotland for involving young people in planning and/or delivery of health and social care services are NOT effective?

5 - Please tell us why you DON'T KNOW whether the current arrangements in Scotland for involving young people in planning and/or delivery of health and social care services are effective?

6 - Are there any gaps in the current arrangements in Scotland for involving young people in planning and/or delivery of health and social care services?

Yes No Don't know

7 - If there are gaps in the current arrangements in Scotland for involving young people in planning and/or delivery of health and social care services, please describe here?

8 - Would the development of a pan-Scotland collaborative approach to involving young people in planning and/or delivery of health and social care services be FEASIBLE?

Yes No Don't know

9 - Please tell us why you think that the development of a pan-Scotland collaborative approach to involving young people in planning and/or delivery of health and social care services IS feasible?

10 - Please tell us why you think that the development of a pan-Scotland collaborative approach to involving young people in planning and/or delivery of health and social care services is NOT feasible?

11 - Would the development of a pan-Scotland collaborative approach to involving young people in planning and/or delivery of health and social care services be WELCOME?

Yes No Don't know

12 - Please tell us why you think that the development of a pan-Scotland collaborative approach to involving young people in planning and/or delivery of health and social care services **WOULD BE** welcome?

13 - Please tell us why you think that the development of a pan-Scotland collaborative approach to involving young people in planning and/or delivery of health and social care services would **NOT** be welcome?

14 - What would be the impacts on your organisation of the development of a pan-Scotland collaborative approach to involving young people in planning and/or delivery of health and social care services?

15 - How could a truly collaborative pan-Scotland approach to involving young people in planning and/or delivery of health and social care services be ensured?

16 - Please tell us which sector you work in?

17 - Please tell us which NHS Board you work in?

18 - Please tell us which local authority you work in?

19 - If you have any other comments, please provide them here:

Young People's Survey

1 - Do you think that it is a good idea to get young people's voices heard when people are planning how your health and social care is provided?

Yes No Don't know

2 - Please tell us why you think that it **IS** a good idea to get young people's voices heard when people are planning how your health and social care is provided?

3 - Please tell us why you **DON'T** think that it's a good idea to get young people's voices heard when people are planning how your health and social care is provided?

4 - Do you think that young people's voices are already heard by people who are planning how your health and social care is provided?

Yes No Don't know

5 - Please tell us about how young people's voices are heard by people who are planning how your health and social care is provided?

6 - Please tell us why you don't think that young people's voices are heard by people who are planning how your health and social care is provided?

7 - Do you use any of these to get your voice heard about your health and social care?

Family members and carers

Doctors or Nurses or other health and social care workers

Social media e.g. Facebook, WhatsApp, Snapchat, Instagram, Twitter

Websites e.g. Our Voice, Patient Opinion

Other (please specify)

8 - If you want to say something about how your health and social care is provided just now, how do you do that?

9 - If you want to say anything else about getting young people's voices heard when people are planning how your health and social care is provided, please write it down here?

10 - Please tell us if you are responding to this survey as

A young person

An adult

Other (please specify)

11 - Please tell us where you live?

Appendix E - Response to the surveys

Response to the adult survey

Table 10: Adult respondents by sector

Answer Options	Response Percent	Response Count
NHS	50%	52
Third / Voluntary Sector	32%	33
Local Authority	11%	11
Independent Sector	3%	3
Other (please specify)	5%	5
<i>answered question</i>		104

Other included: Education, Scottish Parliament, Social work, Care and learning, Health and Social Care Partnership

Table 11: Adult respondents from NHS Boards

Answer Options	Response Percent	Response Count
NHS Lanarkshire	35%	18
NHS Greater Glasgow & Clyde	21%	11
NHS Forth Valley	8%	4
NHS Lothian	8%	4
NHS Fife	6%	3
NHS Grampian	6%	3
NHS Tayside	6%	3
NHS Dumfries & Galloway	4%	2
NHS Ayrshire & Arran	2%	1
Healthcare Improvement Scotland	2%	1
Other (please specify)	4%	2
<i>answered question</i>		52

Other: works across several NHS Boards

Table 12: Adult respondents who worked in local authorities

Answer Options	Response Percent	Response Count
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Highland	36%	4
South Lanarkshire	27%	3
East Ayrshire	9%	1
Falkirk	9%	1
Orkney Islands	9%	1
Scottish Borders	9%	1
<i>answered question</i>		11

Response to the young people's survey

Table 13: Respondents to the young people's survey

Answer Options	Response Percent	Response Count
A young person	68%	30
An adult	20%	9
Other (please specify)	11%	5
<i>answered question</i>		44

Other included: On behalf of a young person, my son; Paediatric nurse; Professional - working with young people; Professional; Professional in social care

Table 14: Local authorities where young respondents lived

Answer Options	Response Percent	Response Count
Dumfries & Galloway	19%	8
East Ayrshire	16%	7
Glasgow City	9%	4
Highland	7%	3
Dundee City	5%	2
Edinburgh, City of	5%	2
Fife	5%	2

North Ayrshire	5%	2
North Lanarkshire	5%	2
Angus	2%	1
Argyll & Bute	2%	1
Clackmannanshire	2%	1
Falkirk	2%	1
Inverclyde	2%	1
Renfrewshire	2%	1
Scottish Borders	2%	1
South Ayrshire	2%	1
South Lanarkshire	2%	1
Stirling	2%	1
West Lothian	2%	1
<i>answered question</i>		43

Appendix F: Literature review search terms

Table 7 shows the search terms used. The bibliographic databases that were searched were: ASSIA, CINAHL, Emerald, MEDLINE, AMED, Embase, ERIC and HMIC, within the following parameters:

- 5 years (January 2012–January 2017)
- English language
- Scotland, UK and Europe
- Full articles only

The parameters were extended to include all English language articles found; and broadened the timeframe for publication to 2004–2017 as very few articles were identified within the original timeframe. After the filtering, 63 articles were screened, with 14 articles being eligible for the review. Articles which addressed ‘personal’ decision making, affecting children and young people as individuals e.g. about treatment for a condition, were excluded: the focus was on decision-making affecting young people as groups.

Table 1: Literature review search terms

Youth OR young
AND
Particip* OR engag* OR forum OR champion OR parliament OR partner*
AND
Health OR Social OR local authority
AND
Plan* OR delivery OR co-produc* OR design

Appendix G: Mapping Summary

Table 15: Mapped structures/organisations by country

	#	%
Scotland	39	71%
UK	15	27%
England	1	2%
	55	100%

Table 16: Mapped structures/organisations by sector

	#	%
Third sector	32	58%
Set up by Government	10	18%
Statutory	4	7%
Other	9	16%
	55	100%

Appendix H: Specific examples provided by survey respondents

Additionally, several specific local/individual initiatives were mentioned by 14 (7%) survey respondents.

- “There have been some attempts in some location/organisations e.g. Young carers, Action on Smoking and Health, Walk the walk to involve young people in service provision.”
- “Locally in East Ayrshire we have a number of arrangements to engage with young people it is not specific to health and social care but we would use these mechanisms to engage and consult with young people.”
- “Young people are incorporated into the interview selection process for services - such as a Life Coach/Children’s Rights Officer/Peer Mentor Co-ordinator within Falkirk.”
- “North West Glasgow Youth Network have a Youth Committee which runs parallel to shape the future and identify priorities for practitioners/professionals who are members of the this group.”
- “Glasgow City Schools Health and Well-being Survey - Pupils have been involved planning Health and Wellbeing action plans in relation to the recent survey findings.”
- “In a number of areas wellbeing surveys are used to gather data from children and young people about their lived experience. This data is always anonymous but gives organisations with lead responsibility for planning robust information to shape local plans from. This approach is delivered by both the Realigning Children’s Service programme and partnership between some Community Planning Partnerships and Dartington Social Research Unit.”
- “There is a current pilot underway in Edinburgh to develop a model for the involvement of children and young people in Children’s Services Plans and it is envisaged on completion the outcomes of this will be shared more widely to ensure the voices of children are captured across the country.”
- “Funding for new participation role secured for within NHS Dumfries & Galloway Child and Adolescent Mental Health Services Service (Young People’s Participation Worker¹⁸).”
- “There have been forums/discussion groups with young service users within some of the clinical specialties at the Glasgow Children’s Hospital.”
- “NHS Lanarkshire has held an event with teenagers to explore their views on using our health services.”
- “In our [NHS Lanarkshire] Paediatric Wards, our Senior Management Team undertake walk rounds to speak to the children about their care experience during their stay in hospital. This has informed a number of changes.”

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<https://jobs.scot.nhs.uk/uploads/15/1034.16%20Young%20Peoples%20participation%20worker%20A%20DMIN001PHBHCRM.5.16.pdf>

- “Development assistant posts have been available in our Local Authority area¹⁹, for young people to work alongside qualified workers, and educate different services regarding what being caring experienced meant for them.”
- “Monthly group meeting take place where young people’s voices are listened to with regards to moving positive changes for the future²⁰.”
- “Although no formal process is in place Scottish Borders Council (Youth Voice team) engages with young people through the school and out of school club networks as and when required.”

¹⁹ Respondent did not provide local authority area

²⁰ Respondent did not provide local authority area

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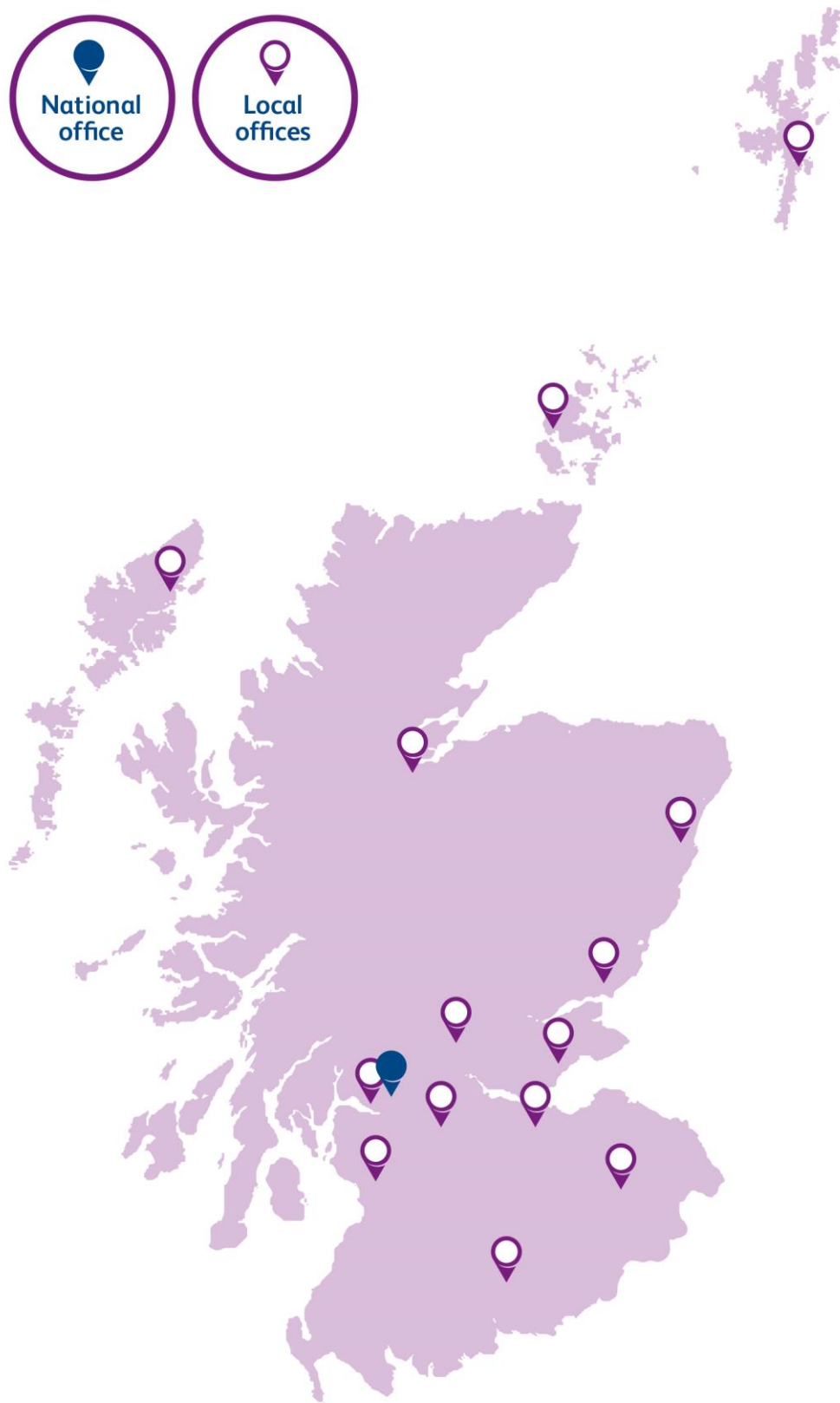
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