

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

Summary Report

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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.

Background

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.

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%: 33) 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 UN 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 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 & 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

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 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.

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 on 31st March 2017.

It is recommended that the Scottish Health Council, in line with its work to support the delivery of the Our Voice framework, explores the following 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, and
 - c. evaluates its impact.

2. How best to develop practitioner capacity and good practice in involving young people.

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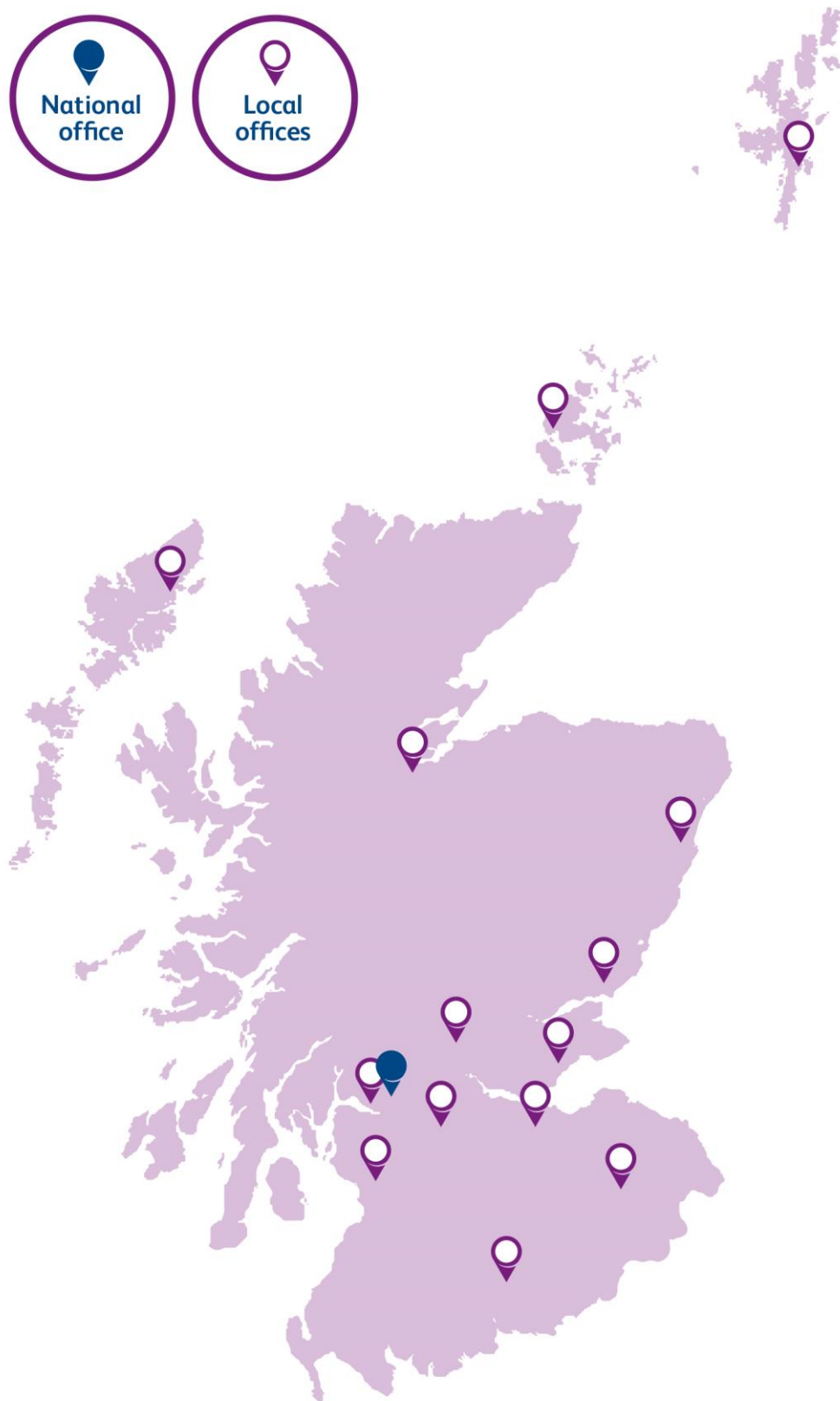
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