

Guide to engagement with families

Participation in Practice

November 2016

Action for Sick Children Scotland



EACH Child and Young Person's Health Matters



***Our Vision** is for best quality
healthcare for children and
young people in Scotland*



Action for Sick Children Scotland (ASCS)



Our Vision is for the best quality healthcare for children and young people in Scotland

Our Mission is to enable every child and young person to exercise their rights to healthcare and to have these rights upheld, and their healthcare needs met, in partnership with their parents, carers and professionals. We do this through direct support and advice, influencing policy and campaigning for service improvement.

A Two Year Old Goes to Hospital

(James Robertson Films)

- https://www.youtube.com/watch?v=s14Q-Bxc_U



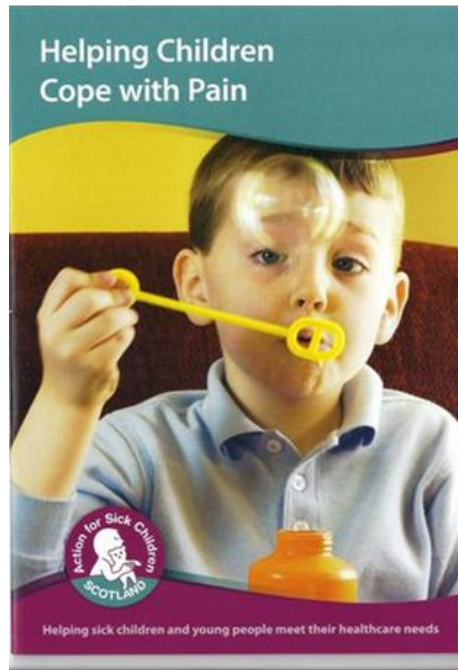
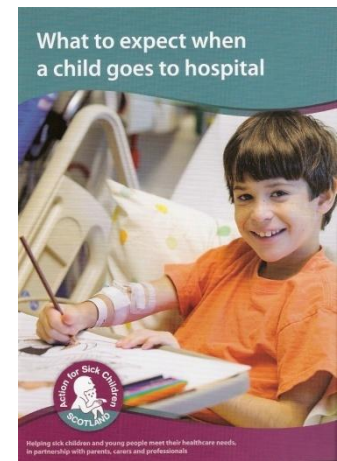
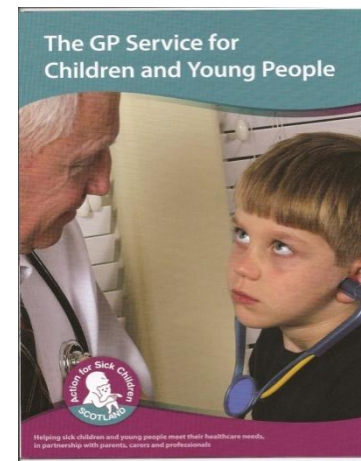
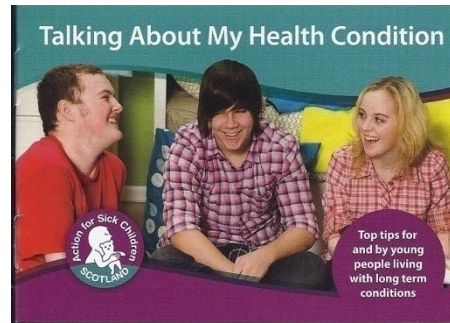
Promoting the Healthcare Rights and Needs of Children and Young People

Working in **partnership** with:

- Scottish Government, National Health Service (NHS) for 45 years: national, regional and local level.
- Working with families, **parents+carers, children+young people** in a 'hands on' way, providing information, support and advice.
- Specific **Projects** e.g. Special Smiles, Lothian Self-Management Project



SOME ASCS RESOURCES

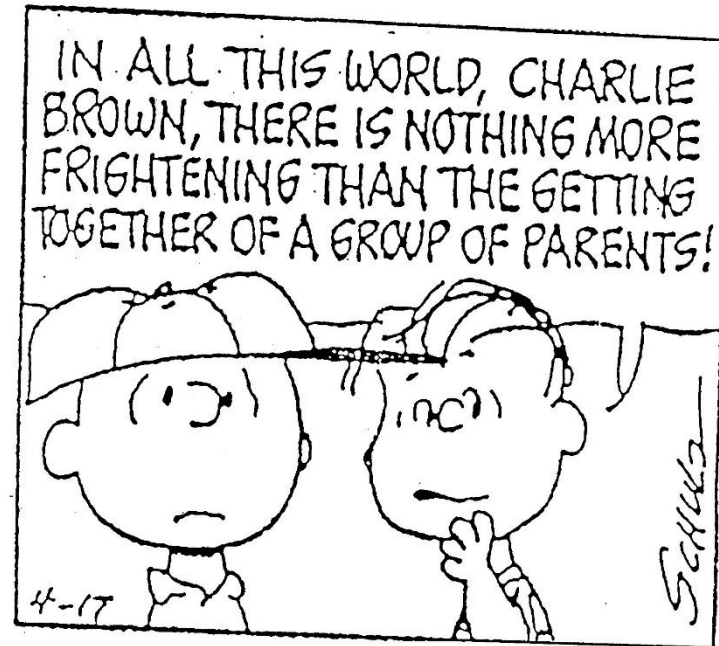
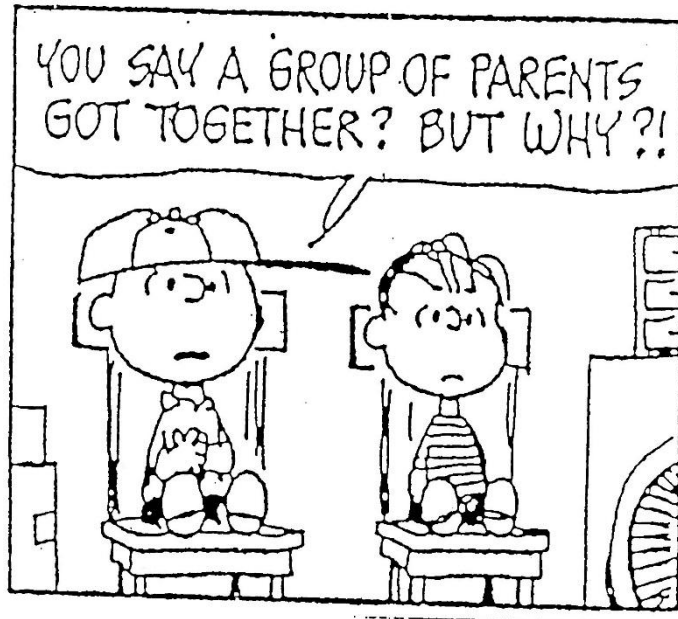


Session Focus

- An introduction to the work of Action for Sick Children Scotland including their work in participation
- The policy background in relation to user involvement
- Theory and practice of participation
- Reasons for engaging with families
- A chance to explore opportunities in relation to health and healthcare settings
- Practical tips for engagement with stakeholders
- Information on other resources and toolkits for participation and engagement



Parent Carer Participation



Defining Participation

- ✓ You asked - we said - you did.
- ✓ Representative
- ✓ Not self interest
- ✓ Engaging in a meaningful way with feedback being used to improve things
- ✓ Asking, listening and doing
- ✓ Pro-active – it is about making sure services meet CYP needs and can change or improve when they need to



Why Participation?

- Effective participation happens when parents have conversations with, and work alongside, professionals in order to design, develop and improve services. This conversation benefits everyone.
- Working with parents helps professionals to understand what needs to happen to develop services that meet families' needs.
- Working with professionals helps parents understand the complexities involved and the challenges faced by the professionals who have to bring about changes to services.

3 Essential ingredients for successful parent carer participation.....

Parent Carer Participation an overview, Contact a Family, March 2012



Policy Background - 1

Better Health, Better Care: Action Plan (2007) – sets out a vision based on mutuality where staff and patients are partners or co-owners giving them a far greater say in the health service.

www.scotland.gov.uk

Patients' Rights Bill – launched in 2010 to reinforce and strengthen SG commitment to place patients at the centre of NHS in Scotland, clarify standards expected of the NHS and set out the rights and responsibilities of patients in a clearer way.

www.scotland.gov.uk

Scottish Health Council – Participation Standard and Participation Toolkit. Information on the Public Partnership Forums (PPF) the link between local communities and Community Health Partnerships (CHPs) (responsible for Health and Social Care services in an area) www.scottishhealthcouncil.org

The Healthcare Quality Strategy for NHS Scotland – putting people at the heart of our NHS

www.scotland.gov.uk/Topics/Health/Policy/Quality-Strategy



Policy Background - 2

Children and Young People (Scotland) Act 2014

www.gov.scot/Topics/People/Young-People/legislation

Scottish Intercollegiate Guidelines Network –

Scottish Health Council – Participation Standard

NHS Boards need to ensure that people have a say in decisions about their care and in the development of local health services. The Participation Standard is a way of measuring how well NHS Boards do this. It is one of the commitments set out in the Scottish Government's [*Better Health, Better Care: Action Plan*](#) to develop a "mutual NHS" where health services meet the needs and preferences of individuals.

Find out the 3 measures:

www.scottishhealthcouncil.org/patient_public_participation/participation_standard/participation_standard.aspx#.WHj67V5vgdU



Policy Background 3

PFPI in Scotland – good practice and mandatory

Patient Focus – the individual's needs in a person-centred way

Public Involvement – the patient, carers and public have a say in the design and shaping of services.

SHC e-participation toolkit :
using online technology
to involve patients,
carers and communities

[e-Participation Toolkit](#) provides examples of how online technology is being used to involve people both in their own care and when designing and delivering local health and care services.

A companion to our [Participation Toolkit](#), which describes how people can be involved through activities in the real world, this Toolkit is designed to complement rather than replace more traditional methods engaging.



UNCRC – Test your knowledge!



illustration : alex leonard

U.N. Convention on the Rights of the Child: Article 42

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Scotland



Children and Young People's Scotland Act 2014 – Part 1

Children and young people's participation in Children's Rights Reports

151 Public authorities should consider how to meaningfully engage with, and support the participation of, children and young people in the preparation of Children's Rights Reports. This is in line with the principles of the UNCRC, specifically Article 12 (a child's right to be heard) and is also central to GIRFEC as well as a range of other Scottish legislation and guidance. Approaches to engagement and participation should involve children and young people who have a range of experiences, views and circumstances and should specifically take account of children and young people who may be marginalized, excluded and/or from a minority group.

Involving families communities and practitioners

170 Engagement in the development of Children's Rights Report should also extend to families, communities and practitioners (both those employed by the public authority and those from the third sector or other public bodies). Public authorities should similarly explore the most appropriate ways to involve people from these different interests, at what point and how.



UNCRC Article 12

Are you listening and am I being heard?

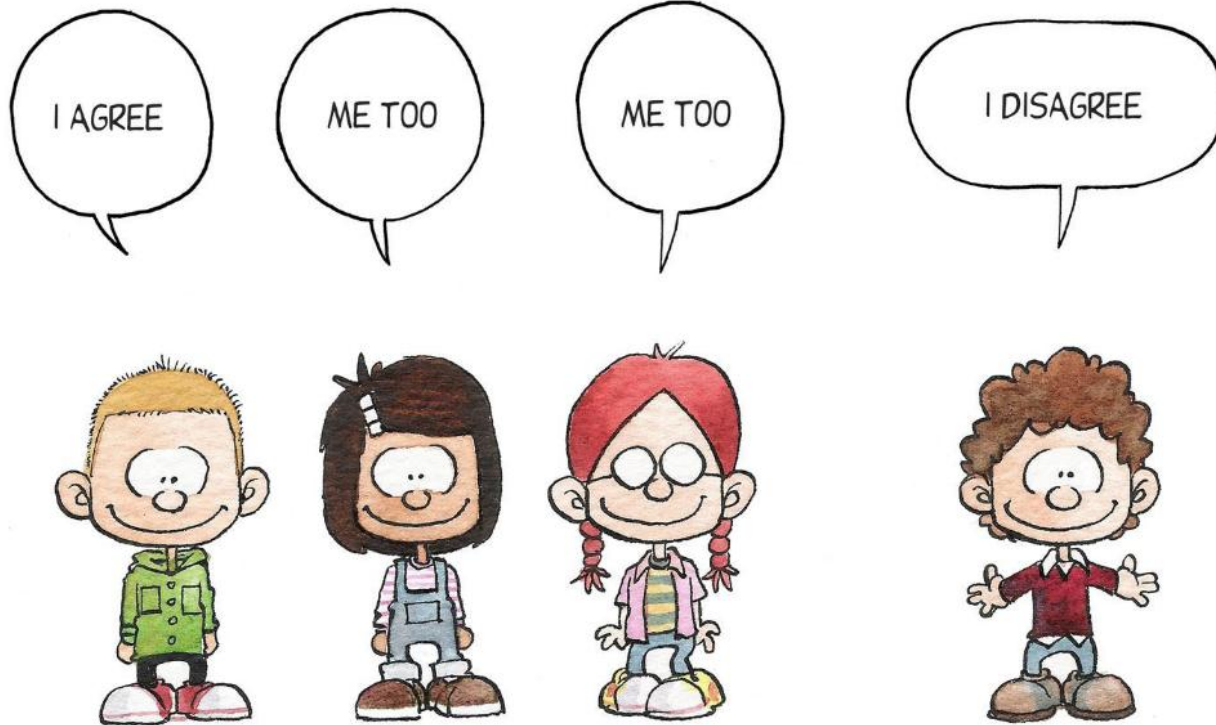


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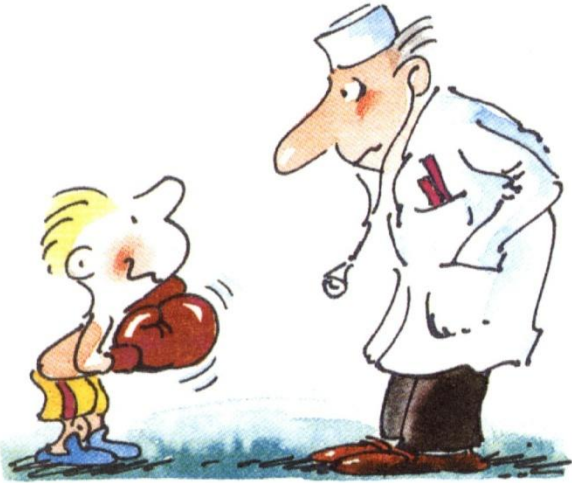
You should have a say in decisions that affect you

U.N. Convention on the Rights of the Child: Article 12

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EACH Article 5



Children and parents have the right to informed participation in all decisions involving their health care. Every child shall be protected from unnecessary medical treatment and investigation.

Young people's interpretation:

Children and parents have the right to know why something is being done so they can help to decide what's best for them and their health care. No medical treatments will be done unless it's absolutely necessary.

What the workshops said:

About Medical personnel: "...always talk to mum" "...leave us out"

"Tell mum before me"

What young people think should happen: "We should know first"

"Our body, Our decision"

"I'd like to help make decision"

"I want to get my own way"

"I wouldn't be sure what drugs would help me"





*Listen to me and hear
what I've got to say*

UNCRC Article 24



You should get the best health care possible

U.N. Convention on the Rights of the Child: Article 24

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UNCRC Article 23



illustration : alex leonard

Children with disabilities should be helped to take part in things

U.N. Convention on the Rights of the Child: Article 23

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UNCRC Article 28

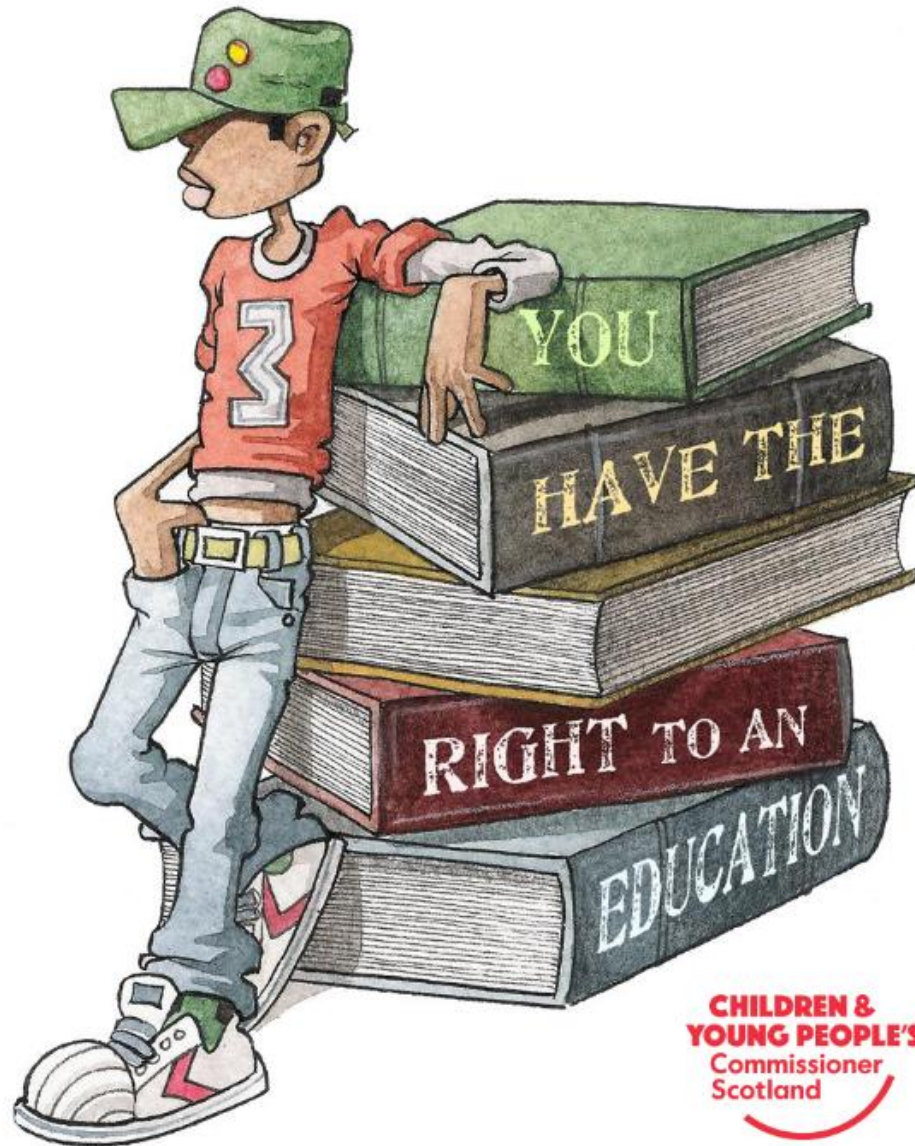


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U.N. Convention on the Rights of the Child: Article 28



UNCRC Article 31

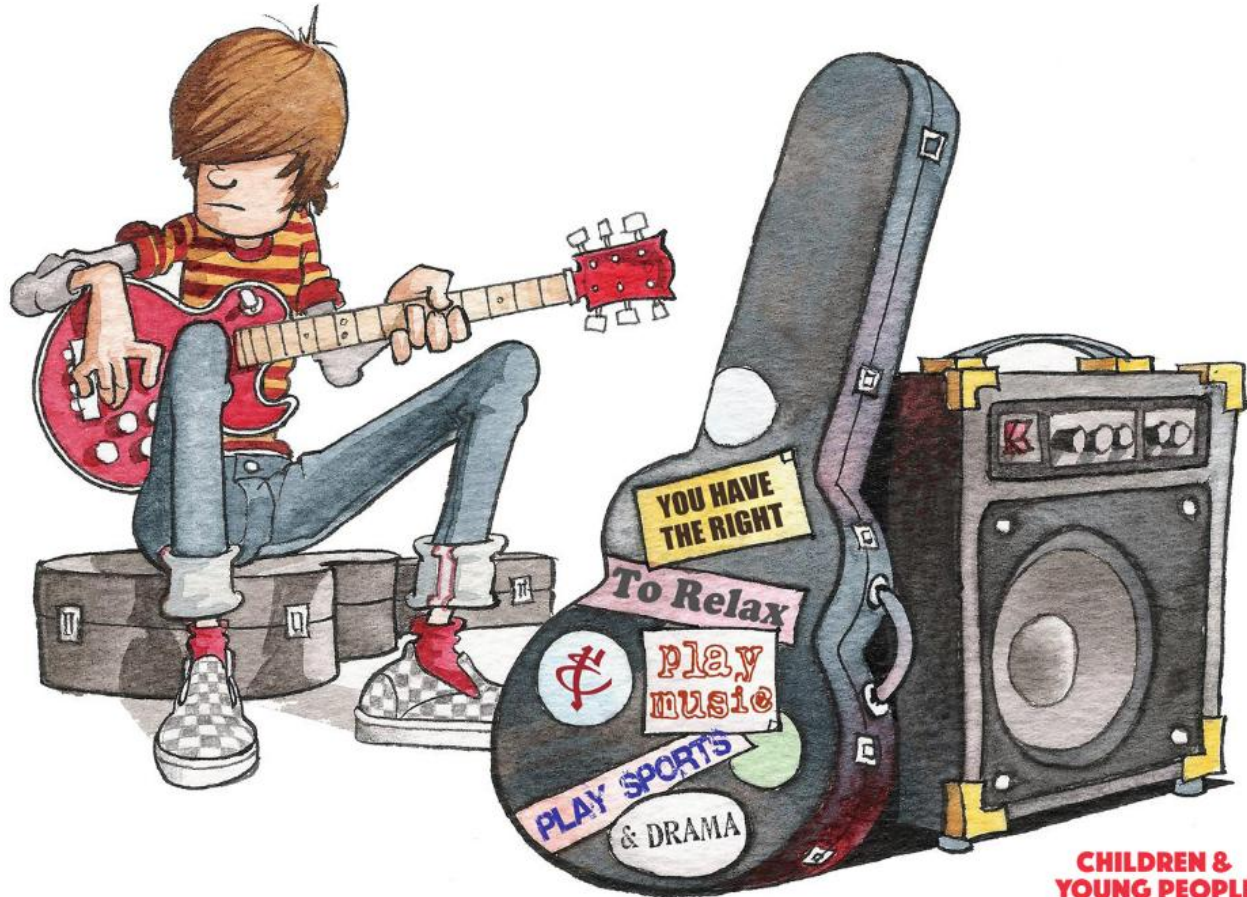


illustration : alex leonard

U.N. Convention on the Rights of the Child: Article 31

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Participation in practice

The Ladder

- Information
- Consultation
- Effective Participation



Participation in practice - 1

Information

- Parents and carers need to be provided with timely, accessible and relevant information in order to access the services and support they need to care for their children.
- Information is power and knowledge – it is key to being confident and able to make the best choices for their children. You can't choose if you do not have the information.



Participation in practice - 2

Consultation

- Is essential and allows service providers to at least know parents' views. All parents will have opinions about the services they receive.
- 2 – way communication, often used to inform parents as to changes which are about to take place.
- Resource holder should reply to parents setting out what has changed as a result of their feedback and explaining why certain changes have not been possible.
- **We asked - you said - we did.....**



Participation in practice - 3

Effective Participation

- Significant step up and requires time and commitment from parents and professionals
- Fosters positive relationships between both
- Can make a big difference to how effective and appropriate services are



Participation ladder

There are a lot of ways services can involve you.

Step 4 Acting together

You are involved in on-going decisions about service developments.

EXAMPLE You are a parent representative on a committee reviewing the effectiveness of local children's services.

Step 3 Deciding together

You have an opportunity to take part in decision-making about service developments.

EXAMPLE You attend meetings about a new service and contribute to the design of the provision.

Step 2 Consultation

You are asked your views on service developments.

EXAMPLE You provide your views about a new service via an online survey.

Step 1 Information

You are provided with information about service developments.

EXAMPLE You sign up to a mailing list of a local service provider.



Getting involved can be daunting!

Not mee onli

Soc user

The you atte

NO the

Participation

| | <i>Typical process</i> | <i>Typical methods</i> | <i>Resource holder stance</i> |
|----------------------|----------------------------|--|---|
| Information | Presentation and promotion | Leaflets, newsletters, displays, social media websites | Here's what we are going to do |
| Consultation | Communication and feedback | Surveys, meetings | Here are our opinions - what do you think? |
| Participation | Partnership building | Working groups/forums | We want to make decisions together |



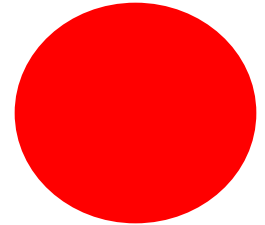
Traffic Lights

My organisation asks children, young people and families for their views

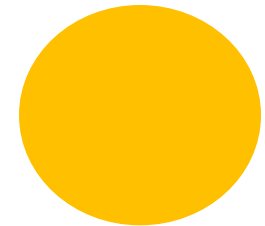
My organisation acts on what children, young people and families tells them

My organisation explains decisions / outcomes to children, young people and families following their input

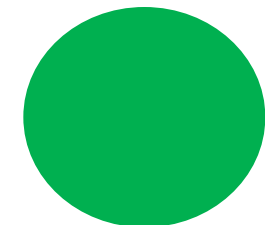
My organisation gives children, young people and families a way to come together to collaborate and change



Undeveloped / disagree



Emerging / not sure



Developed / agree

Participate to Accumulate

What's in it for me?

- Identify families' needs
- Provide evidence for change
- Create services to meet needs
- Service satisfaction
- Professional-parent relationship
- Time and money saving
- Families more able to sustain the care of their child



Participate to Accumulate

What's in it for you?

- Your needs are met
- Better care, better health
- Improves families' experience of services
- Builds trust between CYP, families and professionals
- Ensures that the views of children and families are heard and listened to
- Enables families to sustain their children's care



Let me count the ways.....

- **Being part of a committee, forum etc**
- **Responding to consultations**
- **Comment on patient publications and policies**
- **Interviews**
- **One-off focus group to gather users' views**
- **Contributing to a DVD**
- **Conferences**
- **Regular involvement in focus/subgroups**
- **Short life working/planning/steering group**



Let me count the ways.....

- **Being part of a committee, forum etc.-** [Hospital ROC Group](#), [Scottish Paediatric Safety Programme](#), Health Board child health forum, Project Advisory Group)
- **Responding to consultations** – ASCS PAFFSurvey, CYP (Scotland) Act 2014, [CYPCS Medicines and Toilet Surveys](#)
- **Comment on patient publications and policies** – CYPADM information, Patients' Charter, [ASCS Pain and Needles Guides](#),
- **Interviews** (newsletter article or podcasts LTC, [Enquire](#) and LAC)
- **One-off focus group to gather users' views -**
- **Contributing to a DVD** – [Healthcare Issues for LAC and Young People](#)
- **Conferences** – Transition: Make it Happen! YP from Self-management project, [Scottish Parliament – EACH Campaign](#) and [RCPCH Participation Seminar](#)
- **Regular involvement in focus/subgroups**
(e.g. for Scotland's Disabled Children (fSDC) – Education Task Group)
- **Short life working/planning/steering group**
planning group for Transition conference and standards, [SG Education Guidance and SG Admin of Meds + Healthcare Support in Schools](#)



Feed it Forward – What barriers do you face?

Form 2 circles (equal numbers) facing one another

Each person in the OUTSIDE circle spends 1 minute telling the person opposite them in the INSIDE circle a barrier to meaningful engagement in their organisation.

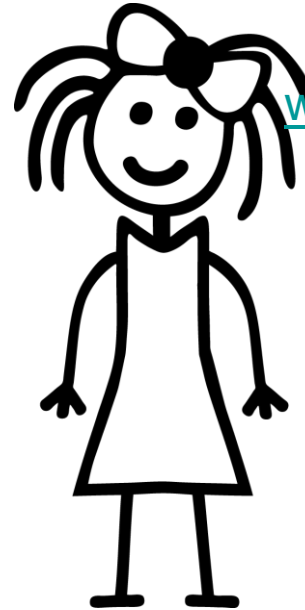
After a minute a bell will sound, then those in the INSIDE circle have to share their ideas on how to solve the other's barrier.

GO!



7 Golden Rules for Participation

- 1 Understand my rights
- 2 A chance to be involved
- 3 Remember – it's my choice
- 4 Value me
- 5 Support me
- 6 Work together
- 7 Keep in touch



[www.cypcs.org.uk/education/
golden-rules](http://www.cypcs.org.uk/education/golden-rules)

Different versions for ages,
communication needs,
resources to support
discussions

Golden Rules

Based on what you have heard today, learned from others or knew already

Draw up a list of best practice principles to guide people involved in participation.

(this could take the form of a
Participation/Engagement Charter)

Groups feed back to plenary



So what now?



Fill in your postcard pledges and drop them in the post-box on your way out in exchange for ...an Action for Sick Children Scotland key ring/bag/magic pen

Your postcards will be sent back to you in a few months to remind you of your engagement takeaway task and actions.

THANK YOU for your Participation today!





www.ascscotland.org.uk

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