



Promoting the healthcare rights and needs of children and young people

Guide to Engagement with Families - as a guide for professionals to facilitate engagement with users.

Facilitators' Notes These notes are to facilitate your delivery of the workshop and should act as a guide rather than in a prescriptive sense. Timings are approximate. The session is designed to take between two to three hours depending on individual team's needs.

Given the increasing importance of enabling user participation and engagement, this toolkit is aimed at a range of professionals who wish to develop their knowledge and skills in this area and in particular gain practical ideas of how to gather their stakeholders' views as part of their every day practice.

The use of the term *families* includes children, young people, parents and carers and reflects the Scottish Government's recommendations for family involvement in the CYP (Scotland) Act 2014 Part 1 Guidance (see Section 7.2 below). While the activities in the guide could be used for both CYP and parents and carers and many of the participation examples given illustrate engagement with children and young people, it is recognised that CYP engagement is distinct from adult participation and may need a separate approach. For those wishing to explore this more fully, there are a number of resources and toolkits given in the Reference section.

This resource was originally developed for professionals in health. However, it could well be used by staff in other sectors for example 3rd Sector agencies who either wish to engage directly with their families or to support families in engaging with statutory and other organisations.

In your introductory remarks, make it clear that you cannot cover everything or anything in depth and stress that the session is a starting point or a refresher. Participants should be encouraged to investigate the area more fully as their time allows. The learning is not just confined to what happens in the session but includes everything they take away, the experience, insight and support of their peers and finally and most importantly their own continuous learning and development.

There are other materials and resources listed in the Contents section below which will enhance participants' knowledge of the area.

It is for individual facilitators to decide how much of the materials they wish to use in one session and whether some materials should be adapted. It is possible to use the materials in "clusters" for a series of sessions.

We are also well aware of the amount of text on some slides, especially the Policy Background slides, and we would expect facilitators to separate this onto additional slides as necessary.

Names of organisations appear in full the first time and thereafter as the acronym.

PDF Slide (PowerPoint) Presentation

Most of the material you will need is included in the Power Point presentation including instructions to participants and answers where necessary. Please see the facilitators' notes for a detailed description of how to conduct the activities.

In addition, you will need a **flip chart** and **paper, pens, name labels, all resources as outlined below** and **handouts as listed**.

Participants will be given packs on arrival (these can be distributed at the end if the facilitator considers it would be a distraction to do so earlier)

The numbered sections in the facilitator notes refer to the numbers on the tabled session outline. The numbers in brackets after each title refer to the slides for that section on both session outline and facilitator's notes.

Contents:

1. PDF Slide (power point) presentation
2. Session Outline – for the detailed session focus please see reverse of session outline document.
3. Users' Guide and Facilitator's Notes
4. List of Handouts:
 - A – Reference List – resources and websites for further information. (Can be added to by facilitator)
 - B – Participation examples (to match to the ladder)
 - C – Pledge Card (these will have to be constructed for your own organisation)
 - D – Picture of blank ladder (optional – or draw onto flipchart paper)
 - E – Evaluation form sample template
5. Other materials free to take away: (hard copies are available from ASCS otherwise see reference list (A))
 - Shaping the services you use – a guide to parent participation (booklet)
 - 7 Golden rules for Participation Children and Young People's Commissioner for Scotland (CYPCS)
 - Royal College of Paediatrics and Child Health (RCPCH) Recipe Book
 - European Association for Children in Hospital (EACH) Young People's Charter
6. Evaluation Form (you may wish to use your own)

NB: The numbered sections below refer to the numbers on the left hand side of the session plan. The numbers in brackets after each section title refer to the PowerPoint slides for that section (on both session plan and facilitator's notes).

1. Welcome and introductions

2. Housekeeping and ground rules (as appropriate to your audience and venue)

These will vary and slides can be inserted here as appropriate to your own settings.

3. Action for Sick Children Scotland (ASCS) (2-6)

1. Ask for a show of hands as to who has heard of the organisation.
2. Then invite comment as to how/why they have used ASCS.

This activity will allow you to gauge audience knowledge of and engagement with the organisation

3. Scene Setting in relation to family engagement:

S.4 – Show the film clip and explain that ASCS grew out of an organisation called Mother Care for Children in Hospital in the late 1950's which in turn was formed after research showed the psychological, social and emotional impact on a child who, on going into hospital, was separated from their parents and family with no warning and no preparation often for long periods of time. This research informed the Platt Report which recommended that children should have the support of a caring figure at times of illness. This is a very powerful example of how the voices of parents and carers and others concerned led to a groundswell of public opinion which went on to campaign for children's fundamental right to be supported by their carers when in hospital and led to a change in hospital practice.

Today of course the reverse is true and parents are expected to be at their child's bedside to participate in the care of their child.

This is a chance to introduce ASCS and family engagement work/group, your own organisation's involvement and the need to engage families in your work and health care in general.

S.5 – All of our work is informed by the needs, views and opinions of parents, carers, children and young people and professionals. We work in partnership with the organisations mentioned and many more. For more information on our work see the ASCS website, Annual Reports and Newsletters.

S.6 – This slide shows samples of ASCS information guides, all of which have been developed and developed in consultation with children, young people, parents, carers and professionals.

There are more examples of our participation activities in later parts of the toolkit.

4. Session Focus (7)

Go through the points on the slide and invite participants to reflect on their own and their organisation's knowledge, skills and practice in relation to these.

This is a good time to ask people to write their expectations of the session on post-it notes. Stick them on your flip-chat or graffiti wall while you discuss them with your group.

The session aims cover these questions:

1. **What** is participation?
2. **Why** is it necessary and beneficial?
3. **How** can we encourage and carry out meaningful engagement?
4. Techniques and Tips

5. Defining participation or family engagement (this is the **what**)

NB: Don't advance to S.9 until after feedback on the definition

1. Brainstorm what is meant by the term **Participation**. Ask participants to work in pairs or small groups and come up with a definition of what participation or engagement means to them.
2. Take feedback from the groups
3. Show slides 9 and 10 and invite discussion. The essential ingredients mentioned at the foot of S.10 are:
 - We asked – you said (we listened) – we did. (**We** in this case is the professional/provider)
 - This is a definition given at an ASCS participation seminar

Participation means engaging in meaningful way with feedback being used to improve things, asking, listening and doing.
 - Listening is fundamental when involving people/engaging them and enabling them to participate. (Look forward to Section 7.3 Article 12 of the UNCRC (16-18))

6. Policy and Background (this is the **why**) (11-13)

This is a fairly theory-heavy section and one suggestion for dealing with it is to ask participants to think about which policies they already know, which they will need to look up afterwards and what they would like to know more about. They should feed this back to their desk partner or groups of three.

1. Policy Background 1 – Some important mile stones
2. Policy Background 2 – Scottish Government, Scottish Intercollegiate Guidelines Network (SIGN), Scottish Health Council (SHC) Participation Standard
3. Policy Background 3 – terms unpacked, e-participation toolkit *

*Invite participants to explore at leisure but stress the importance of Social Media in facilitating engagement.

7. First Principles and the UNCRC (14-22)

1. What do you know about the UNCRC? (Quiz) (14)
Ask participants to stand up if they agree with the true/false statements and then sit down after. You can of course reverse this procedure.

It helps to have the statements on a slide but arrange them “flying-in” or one statement per slide. The important thing is that they do not see what is coming next!

True/False Statements:

- The UNCRC means the United Nations Charter on the Rights of the Child (False – it is convention)
 - The UNCRC is the first international treaty with reference to children and young people (T)
 - The UNCRC was ratified by the UK in 1989 (False - written in 1989, signed 1990 and ratified 1992) (EACH charter was earlier)
 - The UNCRC has been ratified by all 193 UN states (False – 3 have not signed USA, South Sudan and Somalia)
 - The UNCRC is not enforceable (T)
 - Which Article talks about the *right to be involved in decisions that affect me?* Were you aware of this before today? (Article 12)
2. The CYP Scotland Act 2014 – Part 1 (15)
Before moving onto S15 ask participants if they know what the connection is between the CYP Scotland Act and the UNCRC. Why is it included in a toolkit on Participation or CYP and Families’ involvement?

Guidance on Part 1, Section 2 (Duties of Public Authorities in relation to the UNCRC) of the Children and Young People (Scotland) Act

www.gov.scot/Publications/2016/12/4047/downloads

Appendix 4:

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

Then show S 15 with quotes from the Guidance on Part 1. Discussion may ensue on how their organisation/agency ensures that the voice of the child, young person and

family is included in the reporting procedure for how well the principles of UNCRC are embedded in their organisation's practice.

3. Article 12 – keystone of participation (16-18)

You can refer back to the UNCRC quiz and remind participants of the importance of Article 12. This could give rise to a discussion on how well CYP are involved in decision-making relating to their own health. This will depend on time available.

You can explain the connection with the European Association of Children in Hospital (EACH) Charter (10 charter points all related to health rights) and show S17 which shows the work undertaken by ASCS in CYP workshops on understanding the EACH Charter. S 18 shows young people's more user-friendly interpretation and the caption says it all. It is not *Do what I say!* but *Listen to me and hear what I have got to say* which is a very different thing!

Reflection – ask participants to think about whether their organisation does listen to CYP and how it does that.

4. Health Matters – associated UNCRC Articles (19-22)

These slides look at other UNCRC Articles associated with health. Depending on your participants' knowledge, invite them to suggest other related UNCRC Articles such as:

UNCRC 24 – Health

ASCS Vision is for ALL children and young people in Scotland to realise their right to best quality healthcare.

If time permits, you could have a discussion here about “do children have the right to be healthy?” Many people don't understand that this isn't a right – but it is a right to have the best available healthcare. This is a big difference and I think it would be worth asking the group to explore this point.

Mention here could be made of disability, looked after children, groups defined to be seldom heard and “hard to reach”.

UNCRC 23 – Disability

ASCS worked with the CYPSCS on the rights of disabled children to have their medical and healthcare support needs met in schools so that they can continue to attend school and pursue their education.

UNCRC 28 – Education

ASCS worked with the Scottish Government and others on revised Guidance: *Guidance on the education of children unable to attend school due to ill health*, June 2015 www.gov.scot/Publications/2015/06/6846 and subsequently draft Guidance: *Supporting children and young people with healthcare needs in schools*

UNCRC 31 – Play

One of ASCS's areas of work is Dental and Hospital Play preparation, where these strategies are shown to reduce pain, aid compliance and recovery and speed return home. View the Special Smiles DVD here:

www.ascscotland.org.uk/default.asp?page=57

8. Participation in Practice (this is the what) (23-28)

1. The three stages (23-26)

Ask at this point whether participants have seen the Ladder (S 27) and their understanding of the three stages given here (there are sometimes 4 stages as shown

on the ladder (S27) when the 4th stage is **co-production**. This takes the concept of meaningful participation further. “**Co-production** may evolve as a natural progression from participation and takes place when providers, practitioners and service users are involved equally, working together right from the beginning through to the end.” Parent Carer Participation How to Guide (Parent Carer Forum Handbook), Contact a Family www.nnpfc.org.uk/useful-information/

Talk them through the information on the three slides (24-26) and give examples as follows of your own or theirs if possible.

Here are some to use if necessary:

S24 Information

Case 1 - a parent carer met a family support worker in the high street one day and in conversation about their disabled child, it emerged that they were completely unaware of the free nappy service.

Case 2 - This happened on another occasion in relation to not knowing about DLA benefit.

Case 3 – importance of being aware of SWD assessments in relation to provision for a disabled child. Without this, carers often don't ask. If they are refused, they need to know about appeal and how to do that.

It will be evident from the foregoing the importance of information for carers. Stress the dilemma which arises when they do not know what they don't know and therefore cannot ask.

S25 Consultation

Parents of children with complex healthcare needs were tired of having to attend numerous different appointments on different days and in different locations. They fed this back through consultation on the service and were able as a result to set up a one-stop shop service, where clinicians were all available on the same day and at the same place.

S26 Effective Participation

A group of young people in a local authority co-terminous with the local health board formed a task force to examine how YP-friendly services were.

Following an audit of the local paediatric ward, they were able to effect changes to make this more age-appropriate for young people when mobile phones, comfy pillows and cooking facilities were introduced.

2. The Participation Ladder (27)

This is a visual representation of the previous three slides.

You can now ask participants to think about their own organisation in relation to the ladder and reflect on its work in this area.

This is taken from the for Scotland's Disabled Children (fSDC) Guide (see references) *Shaping the services you use*. You can mention how helpful this guide is not only in relation to Health but other service areas e.g. Education, Social Services and general information on Participation. This was written in partnership with Children in Scotland and ASCS.

3. Reflection (28) – this is a different representation of the ladder (previous slide). Ask participants to feedback in pairs or small groups.

Alternatively you can save the feedback for the **9. Traffic Lights Game** which follows. How you manage this depends on your audience's level of understanding and experience.

Participants have an opportunity later in the session **11. Let me count the ways** to put this theory into practice – so it may be best to shorten this section.

9. Traffic Lights Game

Ask participants to consider the statements as they appear on the screen (or are called out) and move to the traffic light which best represents their view of their organisation. (Traffic Lights have been stationed round the room in advance). It is worth conducting a trial round using any statement unrelated to Participation!! For example:

- ❖ 16-year olds are too young to vote (in relation to the 2014 Scottish Independence Referendum OR
- ❖ It is sometimes justified for doctors or nurses to go on strike (in relation to the junior doctors' strike April 2016)

Participation Statements

- 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

If showing these statements on the screen, only show one at a time to keep the element of surprise or otherwise call them out. You may wish to create a power point slide so that you can arrange the statements flying in one at a time.

This activity can be conducted with a very large group providing there is enough room to move about. Depending on time and size of group, you may wish to invite feedback back.

10. Participate to Accumulate (this is the **why**) (30-31)

NB: Do not show the slides before conducting the activity unless you think your audience will not have enough experience to produce reasons.

1. What's in it for me? (professional) (30)
2. What's in it for you? (parent/carer) (31)

These 2 slides appear very similar – they are the reasons why it is beneficial to engage with families from the professionals' point of view (S30) and then from the users' point of view (S31). You can see the overlap.

If your audience has enough experience, ask them to:

- ✓ Pretend to be either a professional or a user and brainstorm in 2s or 4s reasons why you think Engagement is beneficial.
- ✓ Group members note reasons on a sheet of A4 with ether a **P** or a **U** on the back to denote **P** - professional view or **U** – user view.
- ✓ Regroup in groups of 2 or 4 with **2 Ps** and **2 Us** to compare notes.
- ✓ Show the slides and invite feedback and comment.

3. Compare reasons

11. Let me count the ways (32-33)

NB: Do not advance to slide 32 until you have taken feedback from the brainstorm activity. These are all examples of activities from ASCS Family Participation Group.

Acronyms explained:

- Hospital ROC Group – Rights of the Child Group
- ASCS PAFF Survey – Action for Sick Children Scotland Patient Access and Family Facilities
- CYPSC – Children and Young People’s Commissioner in Scotland
- CYPADM – Children and Young People’s Acute Deterioration Management
- LTC – Long Term Condition
- Enquire – National Advice Service for Additional Support for Learning (part of Children in Scotland)
- LAC – Looked after Children

1. Brainstorm ways of participation (32)

This slide sets out a variety of different ways of participation and engaging. Before showing the slide, ask participants to suggest different examples of ways to participate. This can be done as whole group brainstorm or in small groups depending on time. Take feedback and only then show slide 32.

2. Examples from practice

3. Where are we on the ladder? (Either examples given S33 or those on Handout B)

Ask where some of these lie on the ladder of participation. It will help participants to have a model of a ladder in front of them. Alternatively, they could draw an outline ladder on piece of flipchart paper.

Alternative A

Give out HOB - Participation examples and ask participants to show these on their flipchart ladders.

Alternative B – participants produce own examples and attach to ladder.

Suggested answers for Handout B

1. **Different days and different times** – Consultation
2. **YP Hospital Services** – Effective Participation
3. **Hospital Passport** – Effective Participation **Hospi Chill App** – Consultation
4. **What Matters to Me** – Consultation and Effective Participation
5. **Healthcare Support in School** – Consultation ⇔ Participation
6. **Education at times of illness or when too ill to go to school** – Consultation and Effective Participation
7. **UNCRC 25th Anniversary** – Information
8. **ASCS Anaesthetics Survey** – Consultation ⇔ Effective Participation
9. **ASCS Guides to Pain and Needles** – Information and Consultation
10. **EACH Young People’s Charter** – Consultation

12. Pros and Cons (34)

1. Concentric circles (one circle inside the other) – what barriers do you face?

The instructions are on the slide and it is helpful to keep them up as they are too complicated to call out and chaos may ensue!

- ✓ 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.
- ✓ After 1 minute of solution focussed discussion, the bell sounds again and that is the end of the round!
- ✓ Then the OUTSIDE circle takes 1 step left and you find yourself opposite a different partner – this time INSIDE circle shares a barrier or concern for 1 minute and OUTSIDE circle you give solutions for 1 minute.

13. Golden Rules (35-36)

S 35 shows an example of the CYP7S 7 Golden Rules for Participation of children and young people. It is worth having a look at the website www.cyp7s.org.uk/education/golden-rules and in particular reading their Statement on Rights and Participation:

A core principle of the United Nations Convention on the Rights of the Child (UNCRC) is a commitment to ensuring that children and young people have the opportunity to participate in the decisions that affect them, and to be active agents in their own lives.

1. S36 - Participants construct list of best practice principles (Participation Charter) Based on everything they have seen and heard today and other experience, invite participants to construct a Participation Charter in small groups. Conduct whole group feedback and display.

There is also very relevant information in *Shaping the services you use* (page 19)

14. Last Words (37)

1. Summary

Use this time to pick up on any other comments or questions from participants and ask them to think about how they will apply what they have learned today as they fill out their evaluation forms and say their goodbyes.

2. Pledges

Postcards with pledge/takeaway task to complete in their various workplaces. Participants fill in a postcard with their address on the right as normal and their pledges on the left hand side. At the end of the session, post cards are collected by the facilitator who will note the pledge and post the card back to the participant. For example:

My pledge/takeaway task: *I will ensure that my organisation always feeds back on why things have or have not happened.*

3. Evaluation forms

A template example form is included but facilitators should feel free to adapt for their own use.

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