

2020 Edition

Guide to Producing Health Information for Children and Young People



Patient
Information
Forum

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Welcome

About this guide

This guide is for people involved in creating health information for children and young people. It has been produced by the Patient Information Forum (PIF).

It contains practical information to help you produce high-quality, appropriate and effective information resources. We've used the experience of health information providers in the NHS, voluntary and private sectors, and included case studies as examples of good practice.

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Expert panel

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Thanks to Vicki Kirwin, Audiology Specialist, National Deaf Children's Society, for comments on accessibility for children and young people with disabilities. **Thanks to Professor Nisha Dogra**, child and adolescent psychiatry expert at the Greenwood Institute of Child Health, University of Leicester, for extensive input on equality and diversity. See also: O'Reilly M, Ronzoni P, Dogra N. Research with children. London: SAGE Publications, 2013. ISBN: 978-1-4462-0849-6. **Thanks to Jenny Frank**, Programme Manager at the Children's Society, for her substantial contribution to the section on young carers. Thanks also to children's author **Camilla de la Bedoyere**.

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Introduction:

Kath Evans, Chair of the Expert Panel



Children and young people tell us repeatedly they want to be involved in making choices and decisions about their care. Health issues can be scary;

good information reduces anxiety and increases confidence. My experience as a children's nurse has shown me that access to sensitive, accurate, accessible and well-timed information makes the world of difference to physical and emotional wellbeing, helping put them in control, resulting in better outcomes.

Children and young people are eager to broaden their knowledge. We have a duty to identify needs, address concerns and make their healthcare journey well informed. Taking the time to listen, talk with the child or young person and their parents, and where appropriate to communicate through play, are essential interventions.

Creative engagement activities, storytelling, interactive educational games, leaflets in accessible language or online resources are all ways to meet a child or young person's information prescription, whatever health challenges they face.

We must ensure we are accounting for cultural diversity in all our information. This includes gender, sexual orientation, race, beliefs, social class, age and even politics. A critical element is keeping a focus on children and young people who are most vulnerable, examples of this may include:

- Children and young people who have a higher risk of other illnesses because of on-going physical or mental health conditions.
- Those with a statutory entitlement to care and support because of a learning disability or special educational need.
- Those at higher risk of poor health because of socio-economic factors.

And whilst digital engagement grows in popularity and accessibility, remember not all UK children have access to the internet. Different formats are still required.

This rich, practical resource presents evidence, highlights challenges and offers inspiring contemporary case studies and tips.

What does good health information for children and young people look like, what are our opportunities to co-produce information with them? Dip in and find out!

Kath Evans, Director of Children's Nursing/Chair of the Children's Board, Barts Health NHS Trust

Bibliography

NHS England. Delivering universal personalised care. Accessed www.england.nhs.uk June 2020.

Why the right information matters

Key points

- Children and young people have a right to access and be provided with information, to speak up about their own health and wellbeing, and to be listened to.
- Children and young people need access to information they can understand to help them to comprehend their own health and wellbeing. They need time to process information and ask questions.

This is especially important where young people, rather than their parents, may be giving consent for examinations, tests and treatments.
- To improve accessibility, take account of the diversity of your audience. Consider language, culture, social needs, disability, sexual orientation, gender and literacy, as well as age and level of development.
- Find out what works by looking at books, websites, comics, magazines and videos that are popular with your target audience.
- Be sensitive when discussing subjects that may be delicate, frightening, or potentially upsetting.
- Remember that teenagers especially might be acutely embarrassed about their health condition.

Golden rules

1. **Keep sentences short and in a logical order.**
2. **Use simple vocabulary and explain new words. Avoid jargon.**
3. **Numbers can be confusing: use graphics to illustrate.**
4. **Avoid big chunks of text. Choose type sizes and fonts that are easy to read.**
5. **Present facts in a short and punchy way, such as 'Did you know?'**
6. **Provide recap sections and ways to check understanding.**

Chapter one: Why the right information matters

The right to understand

Children and young people **have the right** to access and be provided with information, and to speak up and be listened to about things that affect them. This includes their own health and wellbeing.

They should not be expected to rely solely on parents or other adults to access such information. Instead, they need dedicated information appropriate to their age and level of understanding.

They need information that enables them to participate in decisions about their care, as appropriate to their age, maturity and preferences. **Professional guidance** states that doctors must provide age-appropriate information about a child or young person's condition, tests and treatment options. Doctors should explain who will be involved

in the patient's care and about the right to a second opinion.

Consent

Clear information is vital in this context because young people rather than their parents may be giving **consent** for examinations, tests and treatment. The legal position concerning consent to treatment is different than for adults. Autonomy for young people increases with age. Also with their capacity to understand the decision and its consequences. However, even with younger children, healthcare professionals should always make efforts to help patients understand what is going on. With clear information, many younger children will be informed enough to agree to treatments or to dissent if the treatment is not linked to urgent care.



Chapter one: Why the right information matters

Children and young people's questions about their health and healthcare must be answered truthfully and clearly. Children are capable of understanding difficult concepts and distressing information if it is presented in an honest and accessible way. This includes allowing time and opportunity for questions. It is important not to patronise, to take children seriously and to be honest about any knowledge gaps.

However, intellectual ability to understand a condition is not the same thing as emotional readiness to cope with its impact.

Page 17 discusses writing about sensitive or frightening subjects.

Children and young people need to be provided with accessible and reliable information to find services and support

their decision-making. This is highlighted in [a consultation for England's Chief Medical Officer](#). But too often such information is not there, children and young people cannot find it or it is not clear whether digital information sources are reliable.

The right for children and young people to have an informed voice in their own healthcare is highlighted across a wide and growing range of government policies, explained in more detail in **Chapter 2**.

Understanding this background when your work is helping to meet policy goals can open doors, by creating partnerships and supporting funding applications.

Giving children a voice that will be heard

Children and young people face barriers when they want to express unhappiness with a service. The Bridgewater Community NHS Foundation Trust has created a good example of an online [child-friendly complaints process](#), with easily understood graphics and short, simple explanations.

The general principles of a child-friendly complaints service have been [set out by UNICEF](#).

Tip: 'People who have been through a situation or illness are in the best position to identify what resources will help them.'

Chapter one: Why the right information matters

Support for children with a critically ill parent | Case study | ICUsteps

Critical illness with admission to intensive care is often unexpected, with no chance for families to prepare for a stressful and rapidly changing situation.

Having been in intensive care (ICU) herself when her son was three, the author of this resource understood the situation first-hand. This inspired her to prepare a ready-made toolkit for other families.

The subsequent information and activity book is for children visiting intensive care. It explains where their relative is and what it might be like visiting the ICU. There is also a parent and carer information sheet with ideas about how to support the child.

Each booklet comes with a pack of colouring pencils so that children can work on them while they are visiting the hospital.

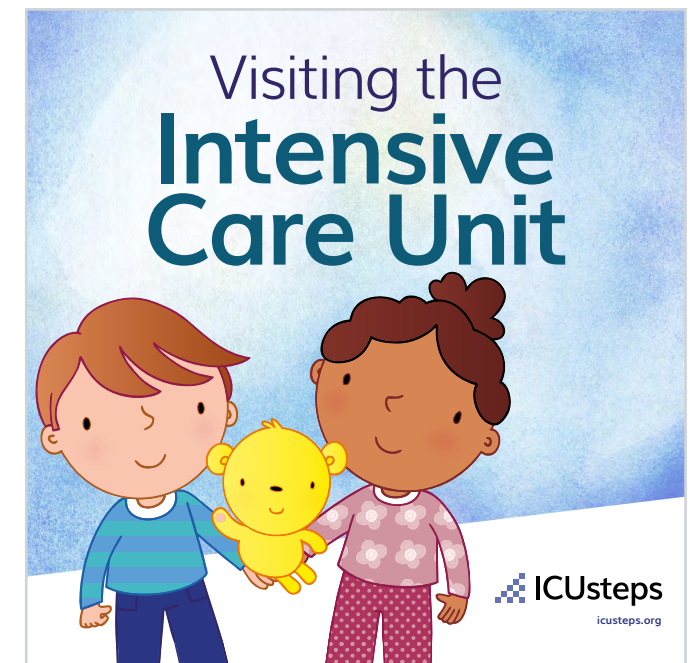
Based on an existing resource in the US, with permission to adapt and develop it, the author worked with specialist children's illustrators and designers. This was to make the booklet as child-friendly as possible.

A primary school teacher, psychologists and a charity with particular expertise in the area of child bereavement provided feedback during development. Also, from the author's own experience volunteering as Information Manager with ICUsteps.

The resource is free to ICUs, who have responded with many positive comments about the comfort and guidance the booklet and information sheet offer to children and families. Healthcare professionals connecting with affected families also report it as being very helpful.

Since publication in 2016, 15,000 copies have been ordered.

See the resources at icusteps.org



Chapter one: Why the right information matters

What works?

There is a lot of health information for children and young people, but it is not always easy to find out what works. This is because the evidence base continues to evolve and the research is not always consistent. There is a list of studies in the bibliography at the end of this chapter.

Children and young people are entitled to their own health information as a matter of ethical principle that should be embedded in all areas of healthcare. However, ongoing evaluation is needed to demonstrate the beneficial impact on health and wellbeing of tailored information for children and young people. It is therefore important to build in strong consultation and evaluation of health information projects. Doing so will also ensure your information is meeting the needs

of your target audience, now and in updates and future projects.

The 2012 A Framework of Outcomes for Young People talks about the importance of supporting young people to develop core social and emotional capabilities. This includes providing information and advice. It suggests several evaluation models to help measure the impact of resources and find out what works.

Growing up with a condition

We know that information needs change as a child grows older. This is relevant both for treatments and for people living with a long-term condition. A four-year-old and a 10-year-old will want to know different things about an X-ray, for instance. And

what worked for a child with asthma at the age of three may not be suitable when they are nine years old. In addition, time since diagnosis may be important. Information needs of a nine-year-old newly diagnosed with asthma will be different to a child of the same age with a lifelong diagnosis.

Coping with feelings

Feelings are important as well as facts. For example, a young person may understand very well how to manage their diabetes, but for social or emotional reasons they may not follow the management plan. Children and young people value information about feelings and how to cope with clinical procedures.

Chapter one: Why the right information matters

Comforting children scared by the COVID-19 pandemic

Case study | Bupa

Calls to their Family Mental Healthline were the driving force for Bupa's animation for young children, helping them to deal with the impact of the COVID-19 pandemic.

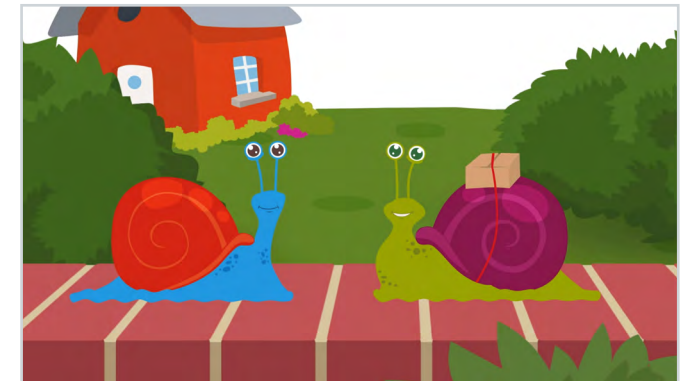
National lockdown laws were in place to try to slow the spread of the virus, which meant many schools were closed and children could not see their friends or some family members. In some cases, the situation was leading to stress, anxiety, upset, anger and worry for young children.

Central to development were careful planning – using the checklist in this booklet on page 49 – and wide consultation.

This approach ensured that the concept of self-soothing through making and using a comfort kit was conveyed in a way that was understandable to the intended age group.

Bupa's partner, the mental health charity Mind, helped refine the tone and language for the animation, with user testing and a survey completed by parents and children. This led to some changes from initial concept, such as featuring real children's voices rather than an adult's voice.

View the animation at bupa.co.uk/newsroom/ourviews/comfort-kit



Tip: 'Use your experience in the field to identify which resources are needed.'

Chapter one: Why the right information matters

The promise of the NHS Long Term Plan

A study by the NHS National Institute for Health Research found that a huge array of children's health information is available as leaflets, toys, games, DVDs and websites. They also found that the field is unregulated, quality is variable, resources are not freely accessible to all, and there are significant gaps in provision.

The Care Quality Commission's review of children and young people's mental health services identified serious gaps in information provision for this group, including children feeling ignored and not being able to find information.

So how can we improve the situation?

The NHS Long Term Plan highlights the health information needs of children and young people. In particular, people with

long-term conditions such as diabetes and asthma, mental health difficulties and challenging differences such as autism. The plan promises that by 2028, children and young people in England, their parents and carers, will experience a 'seamless service' delivered by an integrated health and care system, designed to reduce health inequalities. This will include high-quality information produced and facilitated by a skilled workforce that listens to children and young people, responds to them and meets their needs.

It sets out plans for an information technology revolution for the NHS. This will include working with health information providers to create health-related apps and online resources.

Talk and play – starting school

The children's community speech and language therapy team at Evelina London, part of Guy's and St Thomas' NHS Trust, has produced a short film for parents of children with communication difficulties making the transition to school.

Helping your child start school highlights how to use visual supports such as objects, pictures, signs and written words to support conversations about feelings and new routines.

View the film and other Talk and Play Everyday resources at www.evelinalondon.nhs.uk/communityspeechandlanguage

Chapter one: Why the right information matters

Some children and young people may prefer paper versions of information, so offering traditional and digital formats requires consideration.

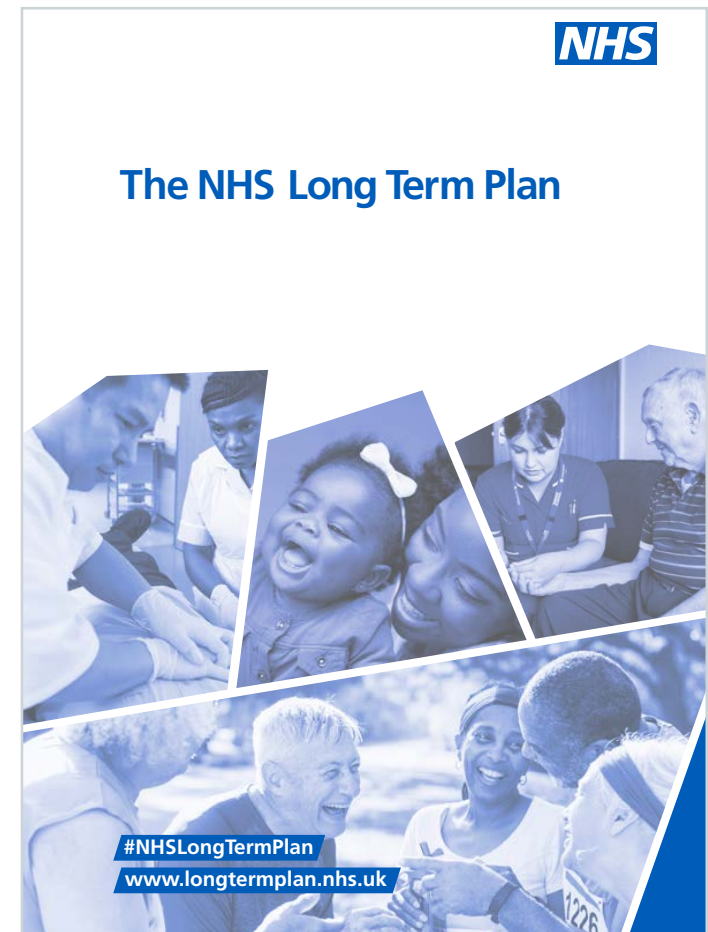
The plan highlights the need for information to help combat the rise in youth violence, with a particular challenge for different health services to communicate better with each other. Also, to deliver a consistent message to the public – especially children and young people – about the role of healthcare and the many avenues of support.

Accessible information

The Long Term Plan builds on previous policy documents such as The National Service Framework (NSF) for Children, Young People and Maternity Services (England).

Although published in 2004 and now superseded by the Long Term Plan, it still provides useful guidance. It says that information should be sensitive to developmental, cultural, social and language differences. Specific provision should be made for disabled children with high communication needs and Special Educational Needs and Disabilities (SEND).

Children and young people should receive information suitable for their age and development that meets their information needs and preferences and reflects their increasing autonomy as they grow up.



Chapter one: Why the right information matters

Benefits of evaluation | Case study | Barts Health NHS Trust

Barts Health NHS Trust demonstrated the effectiveness of service evaluation when developing support for children having an eye removed (enucleation).

Clinicians had noticed that neither parents nor children were talking about problems they were having removing the artificial eye. This was leading to unnecessary anaesthetics and symptoms of post-traumatic stress disorder in children.

Families highlighted several problems including compliance with the artificial eye, school issues, fear and a lack of peer support.

With little literature on the psychosocial impact of enucleation and no best practice guidelines, a service evaluation found 100%

of respondents felt they would benefit from support around artificial eyes and 73% of children did not have information for their school.

New resources were created including support phone calls, children's preparation books, a video demonstrating how to remove an artificial eye and a school information pack.

An Eye Club was started for children to socialise and teach each other about eye removal and care.

Research confirmed that once a child has an enucleation the family needs support, specialist information resources and individualised care.

The team now plans to publish the first retinoblastoma article on information to help address psychosocial aspects of having an artificial eye.



Tip: 'When little or no research is available, evaluation can provide invaluable insights.'

Chapter one: Why the right information matters

Producing information for children and young people needs a particular mindset, approach and range of skills. Children are not just small adults, and teenagers and young adults are not just big children. Bear in mind that past experiences may also shape the way children and young people understand and interpret information.

NICE (National Institute for Health and Care Excellence) is [working on guidance](#) in a number of areas concerning the healthcare of children and young people. This includes Babies, Children and Young People's Experience of Healthcare, planned for publication in April 2021. You can find more detail on how to provide accessible information in **Chapter 4** of this guide.

Information, social prescribing and youth violence

The rise in youth violence is an area that may be addressed in part through social prescribing.

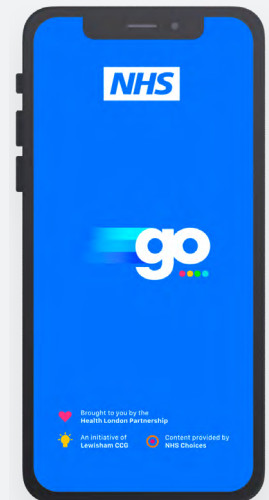
Social prescribing aims to help families address physical, social and emotional challenges such as violence, poverty, obesity, long-term health conditions and low self-esteem. The idea is to do so in creative and innovative ways that are outside a healthcare setting.

Ideally, social prescribing works through integrated care and partnership across

education, health services, social services and the voluntary sector in a local area.

Among many other approaches, information resources for children and young people can be a valuable tool for social prescribers.

For example, The Healthy London Partnership's [NHS GO](#) app.



Chapter one: Why the right information matters

Writing for children and young people

Children and young people are used to reading texts that contain vocabulary and concepts they don't understand; it is intrinsic to the development of their literacy skills. However, if they can't read something or don't understand it, they may just skim over it without asking for clarification.

There are automated tools that can check for readability. For example, the [SMOG readability calculator](#). These tools can only give a rough indication so need to be used in conjunction with other techniques such as user testing and consultation.

See the box on the right for golden rules when writing for children and young people.

Golden rules

- 1. Keep sentences short and order logically.** 'You will fall asleep after the injection' should read, 'You will have an injection, then you will fall asleep.'
- 2. Keep the vocabulary simple and explain new words.** Tricky words can also be written phonetically. For example 'It is called epilepsy (say: epi-lep-see).'
- 3. Numbers and statistics.** Terms such as '60 per cent' may not mean much to many children. Consider saying '6 in 10', or showing data as graphics.
- 4. Big chunks of text are off-putting.** Break up text using different fonts, colours and pictures that add meaning. Place important text into boxes or use a bigger and/or bold font. Consider the size of text and the fonts you are using. Jazzy fonts or block capitals may appeal to children but can be hard to read.
- 5. Call attention to facts.** Devices such as 'It's Amazing!', 'Did you Know?' or 'Top Five Facts' can highlight and position short, succinct and important facts.
- 6. Create opportunities to recap information and reinforce learning.** Try quizzes, multiple-choice questions and bullet points. This gives adults the chance to check whether the child or young person has understood the information, as when using the 'teach-back' health literacy technique.

Chapter one: Why the right information matters

Learning by example

To produce resources at the right level for a particular condition, age group or health experience, it helps to analyse material that's already successful.

Look at books written for children or young people to get an idea of the vocabulary and styles used by experienced writers. Non-fiction books are likely to be most helpful. But remember that most children's writing aims to stretch a child's vocabulary and comprehension skills, whereas writers of health information should keep the text as simple as possible.

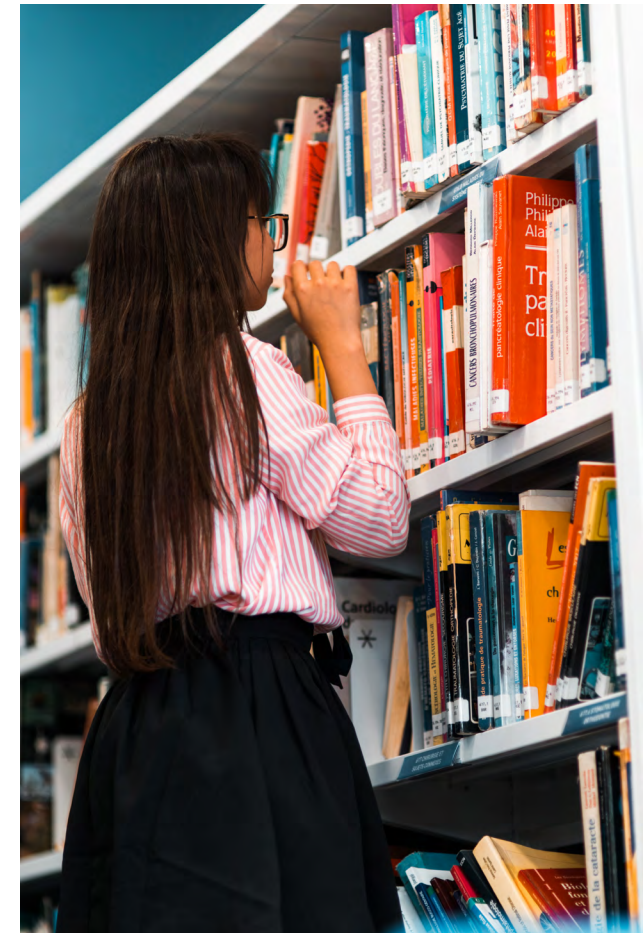
Look at magazines, comics and websites aimed at the target age group. Many of them have imaginative approaches to providing facts and information. Look for

clear layouts and design devices (such as information boxes, activities, artwork and photographs) with impact.

Test out some draft text, design ideas and formats on a group of young readers of the target age group early on in the process.

Aim to work with a group with mixed abilities.

Tip: Camilla de la Bedoyere, educator and author of more than 250 books for children has writing tips on her website. camilladelabedoyere.co.uk



Chapter one: Why the right information matters

Sensitive subjects

Writing about subjects that may be delicate, frightening or potentially upsetting takes particular sensitivity. Mental health and sex are two examples where young people may be especially anxious or worried. Where the child or young person is seeking information relating to a friend or someone they love who is ill, they might be afraid that the person will die. They may need support through a bereavement.

Remember that young people, teenagers in particular, can be crippled by embarrassment over topics that might not appear sensitive at first glance. For example, GPs have reported some young people leaving their athlete's foot for months before coming for treatment because of embarrassment.

Key points to consider

- **It can be helpful to warn the child or young person that the material might be upsetting.** This prepares them emotionally and means they can choose to read it with a supportive adult or friend.
- **Seek guidance from health professionals who work with children and young people in your target audience.** They may be able to suggest a level of detail suitable for the age range or ability level, and provide the health terms that they would expect to use with that audience.
- **Try to keep terms, vocabulary and explanations consistent with other information that the child or young person is likely to be given.** This is especially true for sensitive subjects where the young person may feel uncomfortable seeking clarification or where euphemisms are often used.
- **Keep the information focused on one key area** so that the reader does not have to deal with too much information at once.
- **Use real-life stories to explore difficult subjects.**
- **Ensure the material gives clear guidance** on how and where to get support, help or more information.

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References

The United Nations convention on the rights of the child, 1990.

Accessed: www.unicef.org.uk March 2020.

General Medical Council, 2018.

0-18 years guidance.

Accessed: www.gmc-uk.org March 2020.

British Medical Association, 2018.

Children and young people.

Accessed: www.bma.org.uk March 2020.

Annual Report of the Chief Medical Officer, 2012.

Our children deserve better: Prevention pays.

Accessed: www.gov.uk March 2020.

Bridgewater Community Healthcare NHS Foundation Trust, 2020.

Patient feedback, children and young people.

Accessed www.bridgewater.nhs.uk March 2020.

UNICEF, 2018.

Child-Friendly Complaint Mechanisms.

Accessed www.unicef.org March 2020.

Bröder J, Okan O, Bauer U et al.

Health literacy in childhood and youth: a systematic review of definitions and models. BMC Public Health. 2017. 17, 361. Full paper www.link.springer.com

Bell J, Condren M.

Communication Strategies for Empowering and Protecting Children. J Pediatr Pharmacol Ther. 2016. Mar-Apr; 21(2): 176–184. Full paper: www.ncbi.nlm.nih.gov

Williams A, Noyes J, Chandler-Oatts J et al. 2011. Children's health information matters: Researching the practice of and requirements for age appropriate health information for children and young people. Final Report. NIHR Service Delivery and Organisation Programme.

Full report: www.nets.nihr.ac.uk

Lay summary: www.bangor.ac.uk

Care Quality Commission. 2018.

Are we listening? A review of children and young people's mental health services.

Accessed: www.cqc.org.uk March 2020.

NHS, 2019.

The NHS long term plan.

Accessed www.longtermplan.nhs.uk March 2020.

NHS England. 2019.

Hospital admissions for youths assaulted with sharp objects up almost 60%.

Accessed: www.england.nhs.uk March 2020.

Department of Health, 2004.

National service framework for children, young people and maternity services: Core standards.

Accessed: www.gov.uk March 2020.

The Young Foundation, 2012.

A Framework of Outcomes for Young People

Accessed www.gov.uk March 2020.

NICE, 2020.

Children and young people: A list of all our products on children and young people in development

Accessed: www.nice.org.uk March 2020.

Chapter one: Why the right information matters

Bibliography

Bailey EJ, w CJ, Kruske SG et al.
Culture-specific programs for children and adults from minority groups who have asthma. Cochrane Database of Systematic Reviews 2009, Issue 2. Art. No.: CD006580. Full paper: onlinelibrary.wiley.com

Children's Commissioner
Health Inequalities in Childhood, 2020.
Accessed www.childrenscommissioner.gov.uk
March 2020

Cincinnati Children's Hospital Medical Center, 2012.
Best evidence statement (BEST). Timing of patient/family preoperative education and its relationship to retention of information.
Accessed guidelinecentral.com March 2020.

Fairbrother H, Curtis P, Goyder, E. Making health information meaningful. SSM – Population Health, 2016. 2, 476-484.
Full paper online www.sciencedirect.com

Farinella, M.
The potential of comics in science communication. Journal of Science Communication. 2018. 17 (01), Y01.
Full paper: <https://jcom.sissa.it/>

Graves MM, Roberts MC, Rapoff M et al.
The efficacy of adherence interventions for chronically ill children: a meta-analytic review. J Pediatr Psychol, 2010. 35(4): 368-82.
Full paper: www.jpepsy.oxfordjournals.org

Hieftje K, Edelman EJ, Camenga DR et al. Electronic media-based health interventions promoting behavior change in youth: a systematic review. JAMA Pediatr, 2013. 167(6): 574–80.

Lindsay B, Bradley PM.
Care delivery and self-management strategies for children with epilepsy. Cochrane Database of Systematic Reviews 2010, Issue 12. Art. No.: CD006245.
Full paper: <https://pubmed.ncbi.nlm.nih.gov>

Medical Protection Society. 2016.
Consent - children and young people.
Accessed: www.medicalprotection.org March 2020.

Metcalf B, Henley W, Wilkin T.
Effectiveness of intervention on physical activity of children: systematic review and meta-analysis of controlled trials with objectively measured outcomes (EarlyBird 54). BMJ, 2012. 345:e5888.

National Information Board and NHS England, 2016.
Healthy Children: Transforming Child Health Information.
Accessed: www.england.nhs.uk March 2020.

Salema NE, Elliott RA, Glazebrook C.
A systematic review of adherence-enhancing interventions in adolescents taking long-term medicines. J Adolesc Health, 2011. 49(5):455–66. Full paper: www.ncbi.nlm.nih.gov

Savage E, Beirne PV, Ni Chroinin M et al.
Self-management education for cystic fibrosis. Cochrane Database of Systematic Reviews, 2011. Issue 7. Art. No.: CD007641. Full paper: <https://pubmed.ncbi.nlm.nih.gov>

Involving children and young people

Key points

- Listening to people is sound professional practice. It is a strong theme in UK health policy and a key goal for the NHS. The same philosophy applies to developing health information.
- Consultation from the start means your information will be relevant and well targeted.
- The consultation experience also benefits children because they gain confidence, feel valued and learn that their opinions matter.
- Consulting your target audience is essential if you are seeking, or hold, external quality accreditation.
- From the start, seek to understand your audience and take steps to make involvement as representative and inclusive as you can.
- Children and young people should be involved at all stages, from initial development to evaluation.
- Take care to involve children and young people who might be harder to identify and engage. Often these are the voices services most need to hear from.
- Provide an accessible location or make engagement accessible online.
- Provide refreshments and offer a chance to socialise.
- Activities for small groups work well, but are not for everyone. Consider different preferences and try to offer more than one format.
- Everyone who has contact with children has a duty of care, so your organisation must have a clear safeguarding policy.
- Consider using an independent facilitator.
- Make activities fun. Art, music and drama encourage expression but may not feel comfortable for all children and young people.
- Children and young people are also good facilitators. Offer training to those who would like to facilitate, and encourage an environment of everyone developing themselves. Training and any appropriate qualifications are strong indicators of how much you value their contribution.
- Cover expenses so everyone can afford to take part. Consider paying for children and young people's time and expertise.
- Thank your participants with a letter, prize or certificate. Share the end results.

Chapter two: Involving children and young people

The case for involvement

Every clinician knows that good care starts with listening. Informed choice has become a cornerstone of UK health policy alongside public participation in planning and improving services. The guiding principle is that people should have control over their own health. To do so, they need high-quality information.

As a society, we increasingly recognise that these principles must apply to [children and young people](#) as well as adults.

These changed attitudes were helped by the seminal [Children and Young People's Health Outcomes Forum](#) of 2012. This consulted 2,000 patients, service users, family members and professionals. One finding was that children, young people and their families 'really struggle to have their

voices heard'. In [response](#), the Government and numerous partner organisations pledged to increase efforts within healthcare to involve young patients and their families, and improve care.

You will find a list of NHS and government policies in the references at the end of this chapter at page 32, and more information sources in **Chapter 5** on page 71.

Engaging the audience

[A more recent consultation](#) involving young people asked what they wanted from primary care networks. It found that they wanted to understand what different services primary care can provide. But opportunities for engagement with this audience are often missed.



[A further study](#) that reported its findings in 2020 looked at young people's experiences of using digital technologies to help achieve a healthy lifestyle. It consulted with more than 1,000 young people aged 11–18 years and their parents, using a survey, interviews, focus groups and direct experience recordings.

Chapter two: Involving children and young people

The study demonstrated widespread use of digital technologies among young people wanting information about healthy lifestyle. But concerns about privacy, how to find trustworthy information and making sense of data meant they still needed help from parents. They also valued accreditation from trusted sources such as the NHS and Bupa.

All these valuable findings highlight why a philosophy of involvement and consultation is vital when you are producing health information. There are huge benefits for everyone involved. Including children and young people from the start and working with them as valued partners will:

- Ensure your information is relevant so more likely to be used.
- Offer new insights for professionals working with children and young people.
- Help them learn about their own health.

- Build their confidence and self-esteem.
- Show them that their opinions, ideas and experiences matter.
- Prove that they really can [make a difference](#).

Co-production

One of the key recommendations from the [2020 study](#) cited above underlines this. It says: 'It is important that we include young people in policy development and digital health design. Efforts should be made to involve young people in the co-design and co-creation of digital tools which address their health and data privacy and security needs.'

Children and young people in general will benefit from improved information, and from staff and organisations who are more sensitive to their concerns.

Involvement in developing services

[Involving Children and Young People in Health Services](#), available at nhsconfed.org, offers a view from NHS managers and healthcare professionals.

[Listening to children's views on health services](#) is available from the National Children's Bureau at ncb.org.uk.

Involving your audience is appropriate and invaluable at every stage: from deciding what is needed, through to content development and design, publicity and dissemination, and evaluation.

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Connecting with children and young people

Children and young people are not a homogeneous group. The most excluded – who may need your information the most – can also be the hardest to identify and engage.

Take care to consider their particular needs and involve them in the development of information.

The [National Children's Bureau](#), the [Children's Rights Alliance for England](#) and the [Department of Health](#) have identified several vulnerable and potentially excluded groups, including people who:

- Are in the younger age groups.
- Are from minority ethnic backgrounds.

- Live in disadvantaged households.
- Are in public care.
- Are in the youth justice system.
- Are refugees or seeking asylum.
- Have a disability or special needs.
- Are gay, lesbian or transgender.
- Are teenage parents.
- Have long-term health needs.

Tip: 'Everyone who has contact with children has a duty of care, so your organisation must have a clear safeguarding policy.'



Chapter two: Involving children and young people

Improving access to healthcare for autistic children and young people

Case study | Ambitious about Autism and Whittington Health NHS Trust

Whittington Health NHS Trust wanted to improve services for people with autism. They knew this group struggles to access healthcare services. This is because there is a **lack of knowledge about the condition among healthcare professionals** (HCP).

So, in 2016, the Whittington started working with national charity Ambitious about Autism, which runs a nationwide youth participation programme. The Whittington team knew that they needed the expertise of the people they were trying to help if their work was to be effective.

Ambitious about Autism Youth Patrons and the trust-wide Children and Young People Learning Disability and Autism Working Group led a co-production project. This ensured decisions about improvements and

resource development were shared between healthcare staff and autistic people.

The project led to **a number of initiatives**, including posters, hospital passports and visual stories. The posters are displayed throughout the trust and were developed with additional feedback from the parents of young people with autism.

These resources were used to inform an autism awareness day for HCPs. More than 95% of participants said they could communicate better with autistic patients. There is ongoing monitoring by HCPs and young people with autism to ensure the co-production project continues to enhance services for young people with autism.

View the resource at whittington.nhs.uk



Tip: 'Make sure you are including a representative group of young collaborators.'

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It is also vital to include children and young people who share the attributes or experiences of your target audience.

Look for facts such as population statistics about the condition or health topic you are writing about. For example, if you are targeting childhood obesity, look at prevalence and trends according to age, gender, ethnicity and socioeconomic factors such as education or income. Do the same for the geographical area you plan to cover.

Then, when you are engaging with children and young people, it will be easier to ensure you are including a representative group.

Ask the children and young people you consult with simple questions such as:

- Do you like it?
- Is the information okay?
- What is good about it?

- What needs to be better?
- What's missing?
- Which words do not make sense?
- Are the colours appealing?
- What information needs adding?
- Are the pictures useful?
- Is it easy to read?

Your organisation may already work closely with a broad range of children and young people. For example, an NHS Trust would have a Members' Council or Young People's Forum. Other organisations may be able to help you find children and young people who are willing to advise on your project. They could also help you expand your existing pool of children and young people, so you get wider representation. Try contacting:

- Schools.
- NHS organisations.
- Local authorities.
- Youth organisations.

PIF TICK

In April 2020, **PIF launched an accreditation scheme** for organisations producing evidence-based health and care information for the public.

The scheme supports health information producers to meet a wide range of quality standards. These include information producers demonstrating that they understand and are meeting the needs of their key audiences.

pifonline.org.uk/pif-tick

Trusted
Information
Creator



- Faith groups.
- Voluntary groups.

All these organisations will have many other priorities, so try to fit your work in with them. Better still, show how it helps to meet some of their own objectives.

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You may have to emphasise the benefits of involvement and provide reassurance about the process; they will be protective of the children and young people they work with.

It is important to involve children and young people in a meaningful way, and to be honest about how much influence they will have. Just as you would for adults, set clear objectives so the children or young people know what their contribution will achieve.

Working with children and young people requires sensitivity and flexibility, especially if they are facing serious health problems. Some people may not want to be involved, or they may have a change of heart along the way. You must be prepared to be guided by the child or young person, their parents or carers, and the professionals looking after them.

Points to remember

- **What works well for one person may not suit another.** Some children and young people enjoy group discussions and activities while others feel more comfortable on their own. Some like reading and writing; others do not.
- **Digital media are popular with many children and young people, but do not assume everyone feels confident the format.** Some families do not have access to the technology, and some people just do not enjoy using it.
- **Communication, language or learning difficulties** can create additional barriers to understanding and make it harder for children and young people to engage effectively in consultation.
- **Your approach needs to be appropriate to the age group.** Make things fun and interesting. Use drama, puppets, role-play, music, games, painting and drawing to help communicate and get children talking.
- **Include time for social activities** at the beginning and throughout, mixing work with fun to help everyone feel more relaxed.

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My Life: A friendly way to learn about type 1 diabetes

Case study | Diabetes UK

My Life is a magazine club designed to help children age 7–11 learn about their type 1 diabetes in a fun, friendly and engaging way, using games, letters, mini stories and characters with diabetes.

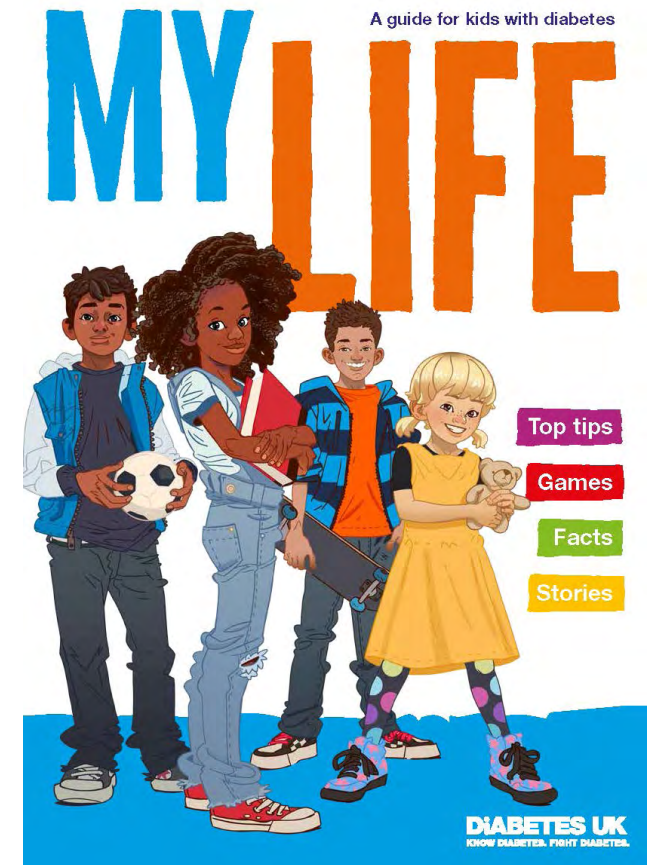
My Life launched in 2014 and was an annual publication. However, insight work showed that children really engage with My Life and need to receive the publication more regularly for it to have more impact.

Based on feedback from 16 children with type 1 diabetes, a main guide for those newly diagnosed was developed, to be followed by termly magazines.

The insights also helped to refresh the My Life characters based on current trends in children's media. The characters are different ages, have a variety of hobbies and diverse experiences of diabetes.

Children with diabetes and their parents are part of an informal user involvement panel for My Life and contribute ideas for features, review content for different sections, review character illustrations and page designs.

Find out more at www.diabetes.org.uk



Tip: 'Don't lose sight of the fact that your audience are children and any products you produce for them need not only to meet their clinical needs but also their expectations of reading materials. Remember, you're 'competing' with commercial, fun products too.'

Chapter two: Involving children and young people

Safeguarding children

Everyone who has contact with children has a duty of care, so your organisation must have a clear safeguarding policy. If you need information and advice, visit the NSPCC www.nspcc.org.uk

It may make sense to offer some alternative ways for children and young people to get involved in your project. Try to make sure there is something for everyone.

With discussions and activities, smaller groups often work best, giving people a chance to get acquainted and have a turn. Be aware of peer pressure, which may cause some children or young people to withdraw or give false opinions. You can address this by providing some one-to-one time. It helps to have a facilitator not involved in

the care of the participants or in producing the information. The children and young people will feel freer to give their honest opinions. Having older children lead the younger ones can also work.

Planning meetings

For meetings and group activities, plan the details to ensure a positive experience:

- Provide a safe and comfortable environment.
- Highlight the importance of confidentiality.
- Use music and provide refreshments.
- Plan short sessions out of school hours.
- Provide help with travel arrangements.
- Make sure expenses are covered.
- Accommodate any special needs or disability.
- Consider using video links so that people unable to travel to the venue can still take part.

You might also use online forums, meeting apps such as Zoom, invite comments by email or set up online surveys.

Say thank you

Let the children and young people you are consulting with know how much you value their contribution. For example, via a note from the chief executive, certificates and small prizes. Payment can be problematic, however. For example, if the activity was carried out at school or if it affects a family's benefit payments. But vouchers are usually welcome and do not affect benefits. Remember to share the final result with your group, and explain how their input made a difference.

Useful resources

The NHS National Institute for Health Research has compiled some [top tips from children and young people](#) on involving them in research. Visit invo.org.uk.

Chapter two: Involving children and young people

Young people informing young people about COVID-19

Case study | Barts Health Youth Empowerment Squad

The Youth Empowerment Squad (YES) is the Barts Health NHS Trust's youth forum. It is made up of young people with experience and knowledge of healthcare. They meet monthly with a mission is to improve Barts services by encouraging young people to share their views about their care and highlight good practice.

A major role of YES is to advocate for the needs of young people. Early during the UK COVID-19 'lockdown' in spring 2020, YES noticed that there was little information available specifically for adolescents and young people and decided to fill the gap.

The decision was taken during one of YES's monthly virtual meetings. Such meetings had become the norm for UK working life in

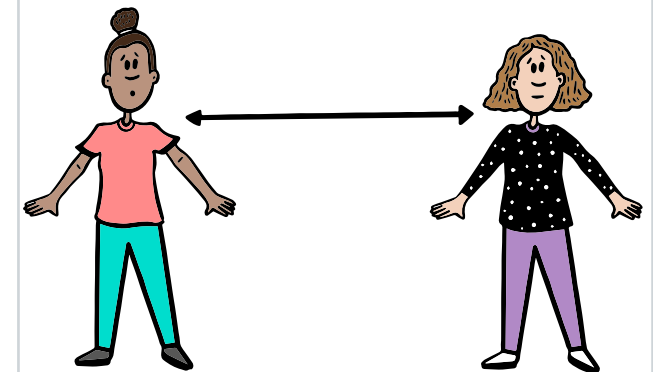
the spring and early summer of 2020. The lockdown prohibited people from meeting physically.

Barts Health staff created the initial draft and YES members reviewed both words and illustrations at each stage before publication.

YES took particular care to ensure it included views from the diverse East London community served by Barts. The need for inclusion became even clearer as statistics from Public Health England show that more people from black, Asian and minority ethnic groups were dying from COVID-19 than those from white ethnic groups.

You can view the leaflet at www.children.bartshealth.nhs.uk

We are all being asked to **PHYSICALLY** distance ourselves from others and to avoid any **UNNECESSARY** contact.



Tip: 'Speed was essential and updates are likely to be needed quickly as COVID-19 news, restrictions and health advice changes.'

Chapter two: Involving children and young people

Self-help support for teenagers with low mood and anxiety | Case study | WYSA



Increasingly high numbers of children and young people are reporting low mood and anxiety with one in nine aged 5–15 years now having a mental health diagnosis. There is a clear need for high-quality early intervention and support resources.

However, the UK clinical lead of WYSA, who works in Child and Adolescent Mental Health Services, found increasing numbers of young people were frustrated with the outdated model of care where very little support is available until after assessment and there is a heavy reliance on worksheets and leaflets.

Using experience-based co-design, young people made clear they wanted to be able to access self-help resources online earlier in their journey. They also wanted the assurance of high-quality support in an online world

where it is hard to be sure of the quality and accuracy of health information.

Based on an existing resource for adults, WYSA is an artificial intelligence self-help tool.

Taking tips and advice used commonly by mental health experts and combining them with common questions and experiences from young service users, the app uses an AI chat interface to encourage young users to explore how they are feeling. The resource then recommends activities, tools or exercises to help boost mood, improve sleep or tackle other goals.

Feedback from trialling helped develop clinical safety pathways and the app now has high scores for clinical safety and assurance as well as an award for the Best Health and

Care app 2020. Subsequent development ensures that WYSA grows and evolves in line with the ideas of young people.

A study showed that the use of WYSA by young people in the general population increased perceived emotional resilience and self-efficacy over an eight-week period in young people aged 14 to 18. WYSA has a free service available to young people across the UK and research and a support service available to schools and clinical services.

See the resource at wysa.io

Tip: 'Young people have powerful ideas on how they want their journey to look – listen to them.'

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References

NHS Confederation. No date.
Children and Young People's Health and Wellbeing in Changing Times.
Accessed: www.nhsconfed.org March 2020.

Lewis I, Lenahan C, et al. 2012.
Report of the Children and Young People's Health Outcomes Forum.
Accessed: www.gov.uk March 2020.

Department of Health et al. 2013.
Better health outcomes for children and young people: Our pledge.
Accessed: www.gov.uk March 2020.

Healthy London Partnership and the Association for Young People's Health. 2020.
What do young people want from Primary Care Networks? Key themes and messages from young people.
Accessed: www.healthy london.org March 2020.

Rich E et al, 2020. The Digital Health Generation: the impact of "healthy lifestyle" technologies on young people's learning, identities and health practices. University of Bath, Bath, UK.

La Valle I, Payne L, Gibb J et al. 2012.
Listening to children's views on health provision: A rapid review of the evidence. Published by the National Children's Bureau.
Accessed: www.ncb.org.uk March 2020.

NHS Confederation and Royal College of Paediatrics and Child Health. 2011.
Involving children and young people in health services.
Accessed: www.nhsconfed.org March 2020.

NHS National Institute for Health Research. 2016.
Involving children and young people in research: top tips for researchers.
Accessed: www.invo.org.uk March 2020.

Shaw C, Brady L, Davey C. 2011.
Guidelines for research with children and young people. Published by the National Children's Bureau.
Accessed: www.ncb.org.uk March 2020.

Children's Rights Alliance for England. 2013.
State of children's rights in England: Review of Government action on United Nations' recommendations for strengthening children's rights in the UK.
Accessed: www.crae.org.uk March 2020.
Department of Health. 2011.

You're welcome: Quality criteria for young people friendly health services.
Accessed: www.gov.uk March 2020.

The Westminster Commission on Autism, 2016
A spectrum of obstacles.
Accessed westminsterautismcommission.files.wordpress.com June 2020.

Patient Information Forum, 2020.
PIF quality mark scheme opens to new members.
Accessed: www.pifonline.org.uk March 2020.

Public Health England
Beyond the data: Understanding the impact of COVID-19 on BAME groups
Accessed: <https://assets.publishing.service.gov.uk> June 2020.

NHS Digital
Mental Health of Children and Young People in England 2017.
Accessed: <https://digital.nhs.uk> September 2020.

NHS National Institute for Health Research, 2016.
Involving children and young people in research: top tips for researchers.
Accessed: www.invo.org.uk March 2020.

Chapter two: Involving children and young people

Bibliography

Central Office of Information. 2010.
Getting it right for children and young people:
Overcoming cultural barriers in the NHS so as
to meet their needs.
Accessed: gov.uk March 2020.

Department of Health. 2013.
Annual Report of the Chief Medical Officer 2012.
Our children deserve better: Prevention pays.
Accessed: gov.uk March 2020.

Department of Health et al. 2013.
Better health outcomes for children and
young people: Our pledge.
Accessed: gov.uk March 2020.

Department of Health. 2013.
Improving children and young people's health
outcomes: a system wide response.
Accessed: gov.uk March 2020.

Department of Health. 2013.
Recommendations to improve health of children
and young people.
Accessed gov.uk March 2020.

DHSSPNi. 2009. Families matter: Supporting
families in Northern Ireland.
Accessed: health-ni.gov.uk March 2020.

General Medical Council. 2013.
Good medical practice.
Accessed: gmc-uk.org March 2020.

Lewis I, Lenahan C, et al. 2012.
Report of the Children and Young People's
Health Outcomes Forum.
Accessed: gov.uk March 2020.
See also sub-group reports on: mental health,
public health and prevention, acute illness,
long-term conditions, disability and palliative care.
Available at: gov.uk

NHS, 2019.
The NHS long term plan.
Accessed longtermplan.nhs.uk March 2020.

NHS. 2020.
Accessible Information Standard: Making health
and social care accessible
Accessed: england.nhs.uk March 2020.

NHS England, 2014
Five Year Forward View
Accessed: england.nhs.uk March 2020.

NHS England. 2015.
The NHS Constitution for England.
Accessed: gov.uk March 2020.

NHS England. 2017.
Next Steps on the NHS Five Year Forward View.
Accessed: england.nhs.uk March 2020.

NHS England. 2020.
Involving people in health and care guidance.
Accessed: england.nhs.uk March 2020.

Nursing and Midwifery Council. 2018.
The Code: Professional standards of practice
and behaviour for nurses midwives and nursing
associates.
Accessed: nmc-uk.org March 2020.

Office of the Children's Commissioner. 2013.
We would like to make a change: Children and young
people's participation in strategic health decision-
making.
Accessed: childrenscommissioner.gov.uk March
2020.

Scottish Government.
A route map to the 2020 vision for health and
social care.
Accessed: gov.scot March 2020.

Scottish Government. 2012.
Getting it right for every child.
Accessed: scotland.gov.uk March 2020.

Shaw C, Brady L, Davey C. 2011.
Guidelines for research with children and young
people. Published by the National Children's Bureau.
Accessed: ncb.org.uk March 2020.

Communicating health information

Key points

- Information is just one part of the communication process. It may also involve interaction with healthcare professionals, parents and family, peers and teachers.
- When communicating with children and young people, find out what they want and need to know; listen to them and respect their views; provide information that is appropriate to their age and maturity; use language they can understand; consider the impact of surroundings and non-verbal communication.
- Involve parents, carers and other family members who are important to the child or young person. This might mean offering information they can share and discuss together, or parallel resources with consistent messages and facts.
- Other young people can be effective communicators of health information; peer-to-peer communication is a growing area of work.
- Teachers are another group of obvious influencers: they have the skills, they know their pupils well, and they are trusted as a reliable source of information.
- Although they may be heavy users of social media, young people do not consistently use the internet when seeking health information. Children may not have the skills to assess the reliability of any information they find.
- Evidence about the effectiveness of mobile apps is a growing area. Research suggests young adults value accuracy, security and ease of use.
- When children or young people are likely to be using your resource independently, include clear signposting to more information, advice and support.

Holistic approach

Information is just one aspect of the communication between health and other care professionals, and children or young people. A resource is often part of:

- The entire package of care.
- Communication and engagement with families.
- Work in schools.
- Involvement with the wider community.

Chapter three: Communicating health information

Gentle learning for children affected by motor neurone disease | Case study | Motor Neurone Disease Association

Families affected by motor neurone disease (MND) often find it difficult to talk about the diagnosis with young children. Children will notice the impact of MND but without explanation may feel isolated or think they are somehow to blame for the way things are changing.

The MND Association set out to help children learn about the disease in a gentle way. They used stories, games, activities and sharing of creative writing and artwork. This was via a web-based hub alongside a companion printed storybook.

The main aim is for children affected by MND to build resilience, be more prepared and better able to adjust to the inevitable changes MND will bring.

During development, six families where young children had a close relative with MND were closely involved. The MND Association Children and Young People's Service Development Manager worked with them to ensure their needs were communicated and considered. Three experts in MND care were also involved.

Feedback surveys, monitoring of social media responses, download and order data are all being used for evaluation. There are also plans to interview families after the first year.

View the resources at mndbuddies.org



Tip: 'If working with a design agency, allow them creativity but bear in mind they will need your expertise too – you know your target audience and the type of approach or tone of voice that will work.'

Chapter three: Communicating health information

Principles of communication

The [General Medical Council](#) guidance on communicating with children and young people emphasises that it is important to:

- Establish what they want/need to know.
- Listen to them and respect their views.
- Provide information at the right level for their age and maturity.
- Use language they can understand.
- Consider the impact of surroundings and non-verbal communication.
- Involve their parents or carers.

Honesty is also crucial, despite any instinct to protect children. It can be hard to decide how much they need to know and when. Aim to be reassuring but truthful. However, bear in mind evidence that suggests offering empty reassurance can raise anxiety.

There are various situations in which you might be communicating with children or

young people; some of these are discussed below. When you are communicating the information, do not make assumptions about knowledge and understanding. Start by checking what the children and young people already know.

Consultations

Information you create might be most appropriately given to the child by a healthcare professional during a consultation. People in general [prefer to receive patient information direct from a healthcare professional](#), although we do not know how much this applies to children and young people.

If a child has just been diagnosed with a serious or long-term condition, best practice is usually to arrange a time for the child to come back with their parent or carer to

ask questions and talk about next steps. Having information to take away and review in the meanwhile is helpful. Following up conversations in writing can also be important, as people often forget a lot of what is said in a consultation. This can also be another opportunity for the healthcare professional to reassure the child and engage with them.

While much information is developed by healthcare professionals working directly with children and young people, if this is not the case then it is often important to involve them in creating a resource. Healthcare professionals have invaluable experience to add. They will also be able to advise you on effective ways to promote and distribute your resource among their peers.

Chapter three: Communicating health information

Putting health information into the hands of children and young people | Case study | Xploro.health

Development of this digital platform was driven by the personal experience of Xploro co-founder Dom Raban, when his young teenage daughter was diagnosed with a rare bone cancer. The information the family was given was directed at him and his wife while his daughter wasn't helped to understand what was happening to her, leaving her scared and wary of her treatment team.

Dom set out to create health information specifically for children and young people, using language and interaction models they understand. The first iteration, launched in autumn 2019, is for children with cancer.

The platform includes a smartphone app for patients, a web app for parents and a web management portal for clinicians. It introduces young patients to hospital environments, staff and the care process

through 3D augmented reality interactive models, an artificially intelligent avatar guide and games.

Throughout development, Xploro consulted with young people diagnosed with cancer, parents, clinicians and other stakeholders. They commissioned digital user experience specialists, ran workshops with children and consulted the Children's Advisory Group at charity CLIC Sargent.

Young people were also involved in helping to design and develop a research study. This was through a partnership with Edge Hill University, led by Professor Lucy Bray.

The evaluation with 80 children undergoing a range of procedures showed that children and young people who used Xploro before their procedure had more knowledge about

it, experienced less anxiety and were more satisfied with their care.

Children were also asked about their information needs and preferences.

An expert advisory board of 12 children and their parents now continuously assess the portal, giving ongoing feedback and suggestions for improvements.

View the platform at xploro.health



Chapter three: Communicating health information

Pitfalls to avoid

The following barriers to good communication have been identified by the **National Children's Bureau** in consultation with children and young people:

- Staff talking to parents instead of to the child or young person.
- Using terms children and young people do not understand.
- If there is a lack of respect from professionals (although many staff are kind and respectful).
- Not being involved in decisions or being given the option to be involved.
- Care settings that are unwelcoming or not age appropriate.

These difficulties are amplified for vulnerable people with communication, speech or language disorders, or who lack parental support, for example if they are in care or secure accommodation.

Effective communication is also especially important for young people with long-term conditions who are making the transition to adult services. Do not assume such an audience will know everything about their condition. There is evidence that **young people often lack important information** about their condition as this knowledge has resided with their parents.



Chapter three: Communicating health information

Parents and families

Family-centred care has been the standard that services aspire to. However, there is now increasing recognition that services should be child-centred while acknowledging the presence and importance of the family.

In either case, it is important to involve parents or carers, and siblings. With this in mind, information for children and young people may also cover conditions that affect other people in the family, such as parents or grandparents. Also, there are many thousands of young people who are themselves carers (see page 63). But, you cannot assume that all young people will want their families involved from the outset.

For younger children, this might mean producing a resource their parents can share

with them, such as a storybook. You can see an example of this approach in the case study on the next page by Parkinson's UK.

Asking questions

Try to build in opportunities for the child to ask questions and voice their fears. Prompt sheets can encourage children or young people to identify their information needs and help them to raise their questions during consultations. You can see an example at edgehill.ac.uk/comingtospinalclinic

Ideas or tools for parents to check the accuracy of their child's understanding and identify gaps are also important.

For older age groups, think about providing parallel information resources for young

people and their parents and carers. It is vital that the information provided to everyone in the family is consistent in terms of facts and key messages and that you are promoting a common lexicon and understanding.

Supporting each other

Evaluation is crucial because the evidence for peer support is still mixed although becoming more robust in its favour.

Evaluation of any resources you produce would be an opportunity to add to the body of findings in this area.

Chapter three: Communicating health information

My Gran has Parkinson's | Case study | Parkinson's UK

For very young children, health information should be provided in a format they can share with a trusted adult, such as a parent or teacher. This allows the child to ask questions and express their feelings, and it gives the adult an opportunity to explain and reassure. Older children can also read storybooks on their own.

Parkinson's UK has updated a series of storybooks, featuring a grandmother, grandfather, mother and father. They are aimed at children aged three to seven, to help them understand the condition and how it might affect their family. The books are available free of charge in print or PDF download formats. They offer gentle, high-quality text and illustrations from a

professional author and artist. Children and families helped create the text and chose from a shortlist of design styles during the development process.

The content was developed with input from an educational psychologist, a clinical psychologist, and a Parkinson's UK information support worker who was familiar with common situations and concerns that families face. The charity's in-house editors and diversity experts also played a role in assuring quality.

See the storybooks at:
www.parkinsons.org.uk



Tip: 'User test at every stage to get a real idea of whether what you are doing is what the reader needs and wants.'

Chapter three: Communicating health information

Beyond the family

Other young people may be more trusted than adults as a source of information, and peer-to-peer communication is a growing area of work. Young people can develop programmes, give training, and go on to provide information and support to others.

In addition, many health charities now offer young people the chance to share their experiences online, for example through a moderated forum. This type of service comes with a lot of responsibility for the provider. They will need policies and procedures in place to handle issues such as safeguarding, data protection and bullying.

Consider what you would do if no one answers a post, which would leave the young person feeling even more lonely and isolated. How would you ensure that

damaging or inaccurate information was not shared? Is it simply a forum for support or could it also be used as a channel for education? Peer support forums can also pose real ethical challenges, especially in sensitive areas such as eating disorders and other mental health issues.

At minimum, all this means you would need an experienced moderator to oversee the forum and respond quickly to any problems.

Online communities

For a good example of an online health community for young people, visit actionforme.org.uk. Additionally, the British Heart Foundation runs two peer support groups, [Teen Heart](#) for teenagers and [One Beat](#) for young people aged 18–30.

Teachers are another group of obvious influencers: they have the skills, and they know and understand their pupils well. For example, in England, all schools were due to introduce [health and relationships education](#) in September 2020 while in Scotland, health and wellbeing is already [part of the national curriculum](#). As a result, many health information initiatives are now reaching into schools. The whole-family approach is also useful here, as the pupil's view of teachers can be influenced by cultural factors and attitudes at home.

Podcasts are also rising in popularity with older teenagers, especially when they feature young people themselves. For example, the health podcast series for young people [Health Uncovered](#).

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Health and wellbeing resources for schools

Case study | Monkey Wellbeing

Working with schools can be a powerful way to help children learn about looking after their own health. When you add role-playing and a cuddly monkey, it works even better.

Monkey features in picture books, leaflets, songs, YouTube videos and as a friendly puppet. In the past, Monkey's Guide to Healthy Living and NHS Services was sent to every primary and special school in England as part of a resource pack sent out to support Personal, Social, Health and Economic curriculum lessons. The lessons teach children about NHS services including urgent care and emergency services, explaining where to go for different problems, and also encourage children to follow a healthy lifestyle.

The resources were developed by Monkey's Mum, Helen Sadler, an experienced teacher working with The NHS Institute of Innovation and Improvement with input from NHS staff, and from children and teachers around the country. Experts in video production and British Sign Language interpreters were also contributors.

The project has since expanded to include many more health and wellbeing resources including materials aimed at informing, reassuring and helping children understand and talk about their asthma, having a blood test, having an operation to an introduction to visiting the dentist.

Visit Monkey at: monkeywellbeing.com



Tip: 'Be flexible and never say no. Be really open to lots of different ideas. Set your standards high.'

Chapter three: Communicating health information

Independent information-seeking

For children and young people, the internet, mobile phones and gaming are simply part of their everyday world.

According to [Ofcom](#):

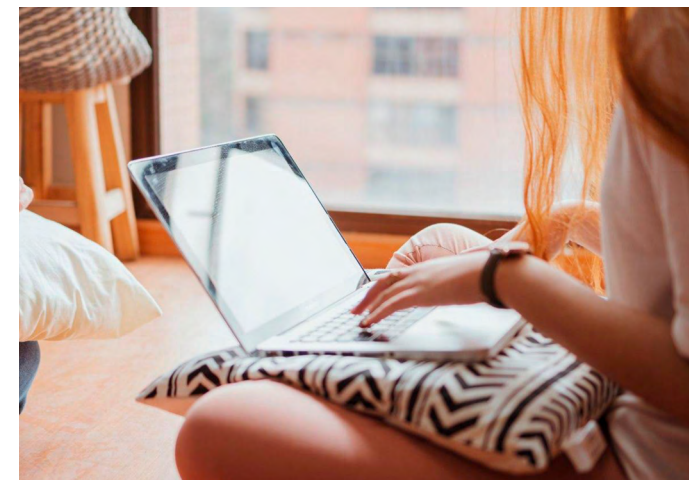
- 45% of children and young people aged 5–15 in the UK owned smartphones in 2019, rising to 83% by age 12–15.
- Among three to four-year-olds, six in 10 are going online, usually via a tablet.
- The proportion of children and young people who watch video on demand has nearly doubled since 2015, with YouTube being by far the most popular video channel. This finding is [confirmed in a more recent study](#) of young people's use of digital healthcare tools.
- 70% of the 8–15 age group have a social media profile, but their favourite

social media channels are changing. For example, Snapchat and WhatsApp are quickly rising in popularity, with newer channels such as TikTok and Twitch attracting increasing attention in the 8–15 age group. Instagram is also a firm favourite with this age group.

It is natural that information providers are investing in online media for this audience. However, just because you build it does not mean they will come. Young people do not consistently make high use of the internet when seeking health information. As the statistics above show, many are social media natives but they have not necessarily acquired the skills to find reliable health information online.

Catch 22 and the Social Switch

[Catch 22 and the Social Switch programme](#) offer free training and resources for practitioners working with young people accessing online resources and social media.



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New children's privacy code for online services

An Age Appropriate Design Code for online services came into force in September 2020 as part of the Data Protection Act 2018.

Administered by the Information Commissioner's Office, there is a 12-month transitional period with organisations expected to conform by 2 September 2021.

Its 15 standards include detailed guidance on best practice for protecting children and young people's privacy online. For example:

- Settings allowing a child's location to be shared switched off by default.
- Privacy settings to be set to high by default.

The code only covers not-for-profit and statutory service apps, games and educational sites **in some circumstances**.

It is becoming increasingly clear that digital literacy issues affect young people's use and understanding of digital tools (see page 51). For this reason, it is important that organisations themselves have expertise in any digital tools and resources they are offering so they can offer support if needed.

Online information aimed at young people is variable in terms of quality and accessibility, and in some therapy areas it is still sorely lacking. You can learn more by reading the studies of online health resources and information seeking, listed in the references at the end of this chapter.

Up-to-date evidence about how many children and young people use the internet to find health information is sparse, with a figure of around 50% suggested. However, a 2020 study survey reported that 70% of its respondents reported using digital

technologies for health purposes, which suggests this figure is rising.

Internet sources are not always trusted but, according to Ofcom, only a little over half of 8–15 year-olds are aware that information on the internet may not always be trustworthy. This awareness rises with age. Additionally, although social media platforms are designed for over 13s, bear in mind that younger children often use a parent or sibling's account, potentially seeing unsuitable or distressing content.

Whatever format you choose, and especially when children or young people are likely to be using the resource independently, always include clear signposting to more information, advice and support.

Chapter three: Communicating health information

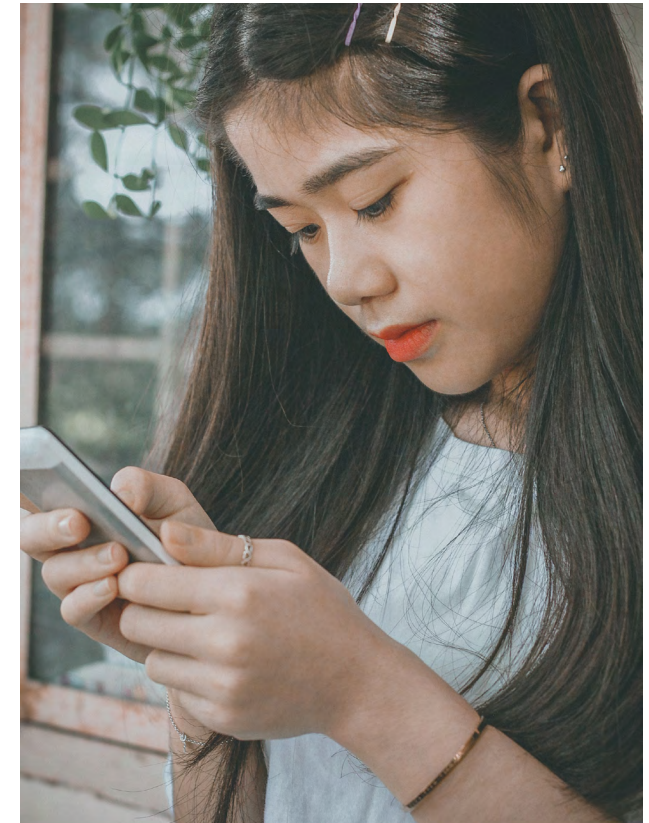
Apps and smart speakers for health

Mobile apps are a fast-growing platform for health-related apps, with more than 100,000 now available. But the evidence about whether they work and what works best is still unclear. As noted on page 11, the NHS Long Term Plan has promised investment in this area. This will include expansion of the [NHS Apps Library](#) of accredited health apps.

Smart speakers are also on the rise with 27% of homes now owning them. So Alexa and Google answers are also now a possible route for health information. But this is a relatively new technology. Although popular among children in older age groups, it tends to be used for fun or quick homework answers rather than in a structured way.

Development of mobile health apps and dialogues needs the same evidence-based approach as other health information, with a particular emphasis on user involvement and evaluation.

There are also as yet largely unexplored avenues by the third sector of viral marketing, focused ads, geocoded phone signals or user-induced triggers. These techniques are already widely used by the commercial sector. An example might be a young person entering a high-risk area for youth violence receiving ads for knife crime awareness apps.



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References

General Medical Council. 2018.
Protecting children and young people: The responsibilities of all doctors.
Accessed: [gmc-uk.org](https://www.gmc-uk.org) March 2020.

McMurtry C, McGrath, P, Chambers, C.
Reassurance can hurt: Parental behavior and painful medical procedures. The Journal of Pediatrics, 2006. 148(4): pp560–561.
Accessed: [jpeds.com](https://www.jpeds.com) August 2020.

Gaglio B, Glasgow RE, Bull, SS.
Do Patient Preference for Health Information Vary by Health Literacy or Numeracy? A Qualitative Assessment. Journal of Health Communication, International Perspectives, 2012. 17, Issue sup3: Advancing Research in Health Literacy.
Accessed: tandfonline.com March 2020.

Bray L et al. The Acceptability and Impact of the Xploro Digital Therapeutic Platform to Inform and Prepare Children for Planned Procedures in a Hospital: Before and After Evaluation Study. Journal of Medical Internet Research, 2020. 22(8), p.e17367.

Bray L, Appleton V, Sharpe A.
The information needs of children having clinical procedures in hospital: Will it hurt? Will I feel scared? What can I do to stay calm?. Child: care, health and development, 2019. 45(5), pp737–743.

La Valle I, Payne L, Gibb J et al. 2012.
Listening to children's views on health provision: A rapid review of the evidence. Published by the National Children's Bureau.
Accessed: [ncb.org.uk](https://www.ncb.org.uk) March 2020.

Bray L, Shaw B, Snodin, J.
Living and managing with the long-term implications of neonatal chronic lung disease: The experiences and perspectives of children and their parents. Heart & Lung: The Journal of Acute and Critical Care, 2015. 44, 6, pp512–16.

Knighting K et al.
A study of childhood cancer survivors' engagement with long-term follow-up care: 'To attend or not to attend, that is the question' European Journal of Oncology Nursing, 2020. 45, 101728, April 1.

Department for Education. 2019.
All pupils will be taught about mental and physical wellbeing.
Accessed: [gov.uk](https://www.gov.uk) March 2020.

Coleman N, Sykes W, Groom C et al.
Peer Support and Children and Young People's Mental Health: Research review, published by the Department for Education, 2017.
Accessed: assets.publishing.services.gov.uk March 2020.

Scottish Government. 2019.
Health and wellbeing in schools.
Accessed: [gov.scot](https://www.gov.scot) March 2020.

Ofcom. 2020.
Children and parents: media use and attitudes report 2019
Accessed: [ofcom.org.uk](https://www.ofcom.org.uk) March 2020.

Rich E et al, 2020. The Digital Health Generation: the impact of "healthy lifestyle" technologies on young people's learning, identities and health practices. University of Bath, Bath, UK.

Information Commissioner's Office. 2020.
Age Appropriate Design: a code of Practice for Online Services.
Accessed: [ico.org.uk](https://www.ico.org.uk) October 2020.

Catch 22.
Online Harms: supporting young people online and offline to prevent harm and build resilience
Accessed: catch-22.org.uk/online-harms September 2020.

Park E, Kwon M.
Health-Related Internet Use by Children and Adolescents: Systematic Review. 2018. J Med Internet Res. Apr; 20(4): e120.
Accessed: [ncbi.nlm.nih.gov](https://www.ncbi.nlm.nih.gov) March 2020.

Chapter three: Communicating health information

Bibliography

Barnard J. 2019.

Digital Future: the New Underclass

[Radio 4 broadcast](#), accessible at [bbc.co.uk](#) March 2020.

Dennison L, Morrison L, Conway G et al.

Opportunities and challenges for smartphone applications in supporting health behaviour change: qualitative study. *J Med Internet Res*, 2013. 15(4): e86. Full paper: [ncbi.nlm.nih.gov/pmc](#)

Henderson EM, Keogh E, Rosser BA et al. Searching the internet for help with pain: adolescent search, coping, and medication behaviour. *Br J Health Psychol*, 2013. 18(1): 218–32.

Henderson, EM, Rosser BA, Keogh E et al. Internet sites offering adolescents help with headache, abdominal pain, and dysmenorrhoea: A description of content, quality, and peer interactions. *Journal of Pediatric Psychology*, 2012. 37(3): 262–71. Full paper: [jpepsy.oxfordjournals.org](#)

Irwin-Rogers K, Pinkney C. Social media as a catalyst and trigger for youth violence, 2017. Accessed: [cdn.catch-22.org.uk/wp-content/uploads/2017/01/Social-Media-as-a-Catalyst-and-Trigger-for-Youth-Violence.pdf](#) October 2020.

Manganello J et al.

The Relationship of Health Literacy With Use of Digital Technology for Health Information. *Journal of Public Health Management and Practice* 2017;23(4), 380-387.

Preston J. 2020.

What do children and young people think about health privacy and trust in the digital world? Accessed: [jennyprestonblog.com](#) March 2020.

Stinson J N, Tucker L, Huber et al. Surfing for juvenile idiopathic arthritis: Perspectives on quality and content of information on the Internet. *The Journal of Rheumatology*, 2009. 36(8): 1755–62. Full paper: [jrheum.org](#)

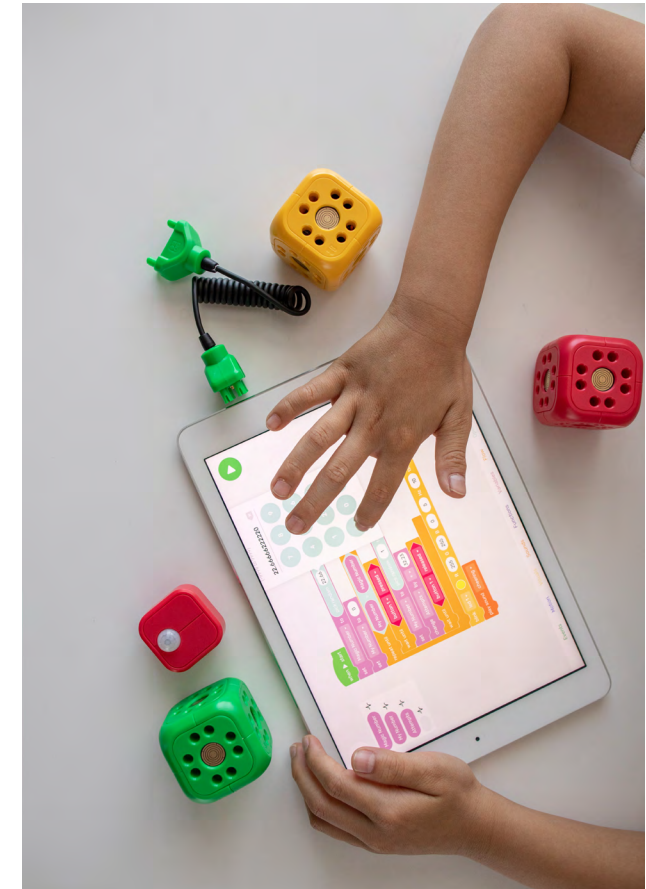
Tolli MV. Effectiveness of peer education interventions for HIV prevention, adolescent pregnancy prevention and sexual health promotion for young people: a systematic review of European studies. *Health Educ Res*, 2012. 27(5): 904–13. Full paper: [her.oxfordjournals.org](#)

Wellburn S, Bettany-Saltikov J, van Schaik P. An evaluation of websites recommended by UK NHS consultants to patients with adolescent idiopathic scoliosis at the first point of diagnosis. *Spine (Phila Pa 1976)*, 2013. 38(18): 1590–4.

Creating high-quality information

Key points

- Assess the need for new information. Make sure the purpose is clear. Can you update or build on existing resources? Check you are not going to duplicate information already available.
- Run through a planning checklist. This should cover: funding and your budget; how you will involve children or young people; safeguarding; expert input and other quality controls; format; creative input; promotion; dissemination; evaluation.
- Consider age groups. Young children under five learn through play; try dolls, teddies, drawing activities or storybooks. They already have a high rate of new media use, but there is debate about how effective or desirable this is. If using digital media, create a resource that can be shared by parent and child.
- Consider how you will address accessibility, including health and digital literacy challenges.
- For children aged five to seven, use short bursts of information and a storytelling approach. By this age, more than half of children access the internet at home on a computer. For digital media, consider material that is designed for sharing with peers, teachers or parents.
- Children aged 8–11 like the question and answer format. Look at popular books, games, websites and apps. Children are still building their confidence as internet users.
- Do not ignore more traditional media: some children do not access the internet anywhere. Not all families have internet access at home. Some children prefer traditional formats.



Chapter four: Creating high-quality information

- By secondary school, digital formats such as videos, games and smartphone apps are familiar and popular. Most teenagers use social networking, but consider protection issues. For young people with a long-term condition, the chance to meet peers in real life is also highly valued.
- Consider how you will address accessibility to physical resources – can the young person find the resource?
- Remember the need to make your material accessible to people with hearing loss, visual impairment and special communication needs.
- Many children do not have English as a first language. Use plain language, consider accessible formats, and plan for translation.
- Consider previous trauma experienced by young people. For example, knife imagery in youth violence awareness material might retraumatise and reinforce young people's perceptions of the world.
- Your choice of format will depend on the needs of your audience, the topic, your budget and the skills available. You may choose to use more than one format if your audience is segmented into different groups or if you want to accommodate a range of learning styles.
- Take cultural factors into account. These are not just ethnicity or language. Consider parents and families in this context as well as the children and young people. Continually reflect on and test your own assumptions about who your audience is and what they want. Think about how the information you're presenting may be perceived by others.
- Young people can be carers, too. They need information about what is happening to their loved one and how to look after their own health.
- Some options include leaflets, comics, picture books or storybooks, audio recordings, videos, websites, social networking, games, apps and helplines.



Chapter four: Creating high-quality information

Getting started

Before starting on any information project, there are important questions to ask yourself and your organisation.

- Why do you need this information?
- What is it aiming to do and how will it be used?
- Who is your target audience and what are their needs?
- Do you need to produce something new?
- Could you build on resources you already have?
- Are you duplicating information that's already out there?

Once you have established the need for information, you can make a clear plan for its development, delivery and evaluation.

Planning checklist

- | | |
|---|--|
| <input checked="" type="checkbox"/> How are you going to involve children or young people? | <input checked="" type="checkbox"/> How will you ensure clinical accuracy and relevance? |
| <input checked="" type="checkbox"/> How are you going to fund development and production? | <input checked="" type="checkbox"/> What format(s) should you use? |
| <input checked="" type="checkbox"/> What is the budget? | <input checked="" type="checkbox"/> Do you need help from creative experts for writing, design, or multimedia? |
| <input checked="" type="checkbox"/> How will you identify the information needs of your audience? | <input checked="" type="checkbox"/> How are you going to disseminate the materials effectively? |
| <input checked="" type="checkbox"/> How are you going to involve children or young people? | <input checked="" type="checkbox"/> How will you keep them up to date? |
| <input checked="" type="checkbox"/> How will you ensure safeguarding? | <input checked="" type="checkbox"/> What will you do for publicity? |
| <input checked="" type="checkbox"/> How will you involve experts in communicating with children (for example, teachers, psychologists, play services or children's nurses)? | <input checked="" type="checkbox"/> How will you evaluate the materials, their impact and their use? |

Chapter four: Creating high-quality information

Information for different audiences

Age groups

It's vital that your information is appropriate to the age, developmental stage and maturity of your audience. One convenient way to think about this is in terms of learning stages used in schools.

For example, in [England's national curriculum](#) this means ages:

- 3 to 5 (Early Years).
- 5 to 7 (Key Stage 1).
- 7 to 11 (Key Stage 2).
- 11 to 14 (Key Stage 3).
- 14 to 16 (Key Stage 4).

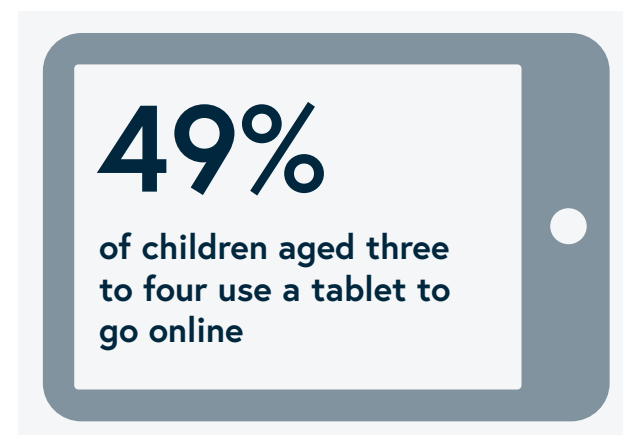
You can also refer to page 15 of this guide, where there is advice from a children's author.

Younger children

Children under five [learn and understand through play](#). As well as talking to young children, you may want to use dolls or teddies or drawing activities. They would also be familiar with short animations and TV programmes.

Storybooks can also help to explain what is happening or what to expect. The case study on page 39 from Parkinson's UK illustrates how this comforting and familiar format can work well for younger children, both in print and digital media.

According to [Ofcom](#), tablets are the most commonly used device for getting online, even among the youngest age groups.



Forty-nine per cent of children aged three to four use a tablet to go online. While there is debate about the educational and developmental merits of digital media for very young children, there is more agreement that they are best designed for use by parent and child together. This is as true for traditional media such as storybooks.

Chapter four: Creating high-quality information

Between five and seven years, children are developing the ability to remember what they have heard and to ask questions. Some can read independently and may be starting to use books and digital formats to find information. However, the spoken word, role-play and pictures are important, and so is guidance from adults.

Consider short bursts of information and a storytelling approach. Look at popular books, websites and games for this age group to get ideas about language, layout and illustration.

By this age, around six in ten children access the internet at home. If you are planning to use digital media, consider material that is designed for sharing with peers, teachers or parents, as this is generally regarded as the most effective educational approach for young children.

How health and digital literacy effects everyone

Health and digital literacy challenges exclude millions of people from accessing and making effective use of health information. This inevitably leads to health inequalities.

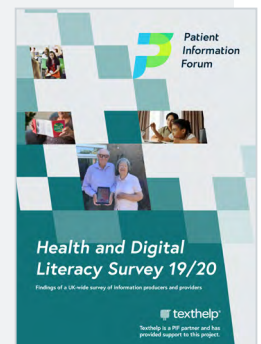
It is also recognised that these challenges may affect anyone at any time. The link is not simply to educational attainment or socio-economic status. People's health and digital literacy levels may be affected by factors such as the stress of a serious diagnosis.

It is therefore a vitally important area to consider when planning health information

for children and young people. This is particularly the case as high-quality health information for this audience will necessarily include supporting information or resources for families, friends, other trusted adults and healthcare professionals.

PIF's 2020 health and digital literacy survey makes good practice recommendations.

View the survey findings and full report at pifonline.org.uk



Chapter four: Creating high-quality information

Older children

Children aged between [eight and eleven](#) can understand more detailed information.

They can:

- Identify the main points of what they have read or heard.
- Ask questions to clarify meaning.
- Explain their ideas and opinions.
- Modify their opinions in light of new information.
- Start making judgements and decisions.

This age group likes the question and answer format. They also enjoy 'amazing facts' or 'did you know?' features. You can visit your local bookseller or children's library for ideas about what is suitable for this age group.

The importance of design and visual appeal cannot be overstated, whether you are using

traditional or digital formats. But take care that images are relevant and well captioned to avoid confusion. You can get ideas from popular games, websites and apps.

Evidence about the best layout and content for children's websites is still being collected. Articles presenting research evidence and design tips are listed in the bibliography at the end of this chapter.

While engagement with social media in this age group is significant, we still need more research into how children use it and what works most effectively.

Digital exclusion

Do not ignore more traditional media, not least because the [Office for National Statistics](#) estimates 60,000 UK children do not access the internet anywhere while

700,000 secondary school age children aren't connected at home. The case study on the next page from the Children's Cancer and Leukaemia Group uses the dual approach of a traditional format and online animations.

Tried and true methods that can be provided in both formats are stickers and reward charts.

Families and schools are a good way to reach children of this age while providing support from trusted adults.



Chapter four: Creating high-quality information

Helping children to deal with hair loss

Case study | Children's Cancer and Leukaemia Group (CCLG)

When young children face losing their hair as a side effect of cancer treatment, it can be difficult to explain it to them. Hair loss can have a distressing impact at any age, and children may worry about what actually happens, whether it will hurt and whether their hair will be gone forever.

CCLG's illustrated storybook *Anna Loses Her Hair* is a children's guide in a familiar format, with easy-to-understand information. It aims to help prepare children and young people for hair loss.

It tells Anna's story as she is diagnosed with cancer and loses her hair. The reader follows her through having her hair cut short before treatment starts, choosing a wig, losing her

hair and growing it back after treatment. A health play specialist in hospital, Penny uses role play to help Anna accept what is happening and feel more comfortable about losing her hair. This reflects that the original author of the book is herself a hospital play specialist. Her text was then developed by CCLG in consultation with families affected by childhood cancer and healthcare professionals.

There is an online animation version to widen accessibility for all young children facing hair loss through cancer treatment.

Download the book at cclg.uk/anna and view the animation at [youtube.com](https://www.youtube.com)



Tip: 'Have full involvement with clinical professionals and end users from the start.'

Chapter four: Creating high-quality information

Teenagers

By secondary school, most young people are learning to verify the accuracy and reliability of information, and form and express their own opinions. They are starting to detect bias, can understand complicated concepts if they are explained clearly, and can search for information online.

Digital formats make sense because young people aged 15 to 16 spend [more than two hours per day online](#). Viewing online videos and playing games on the internet are popular activities with girls and boys alike. Smartphones are ubiquitous.

Teenagers usually respond well to factual information. Question and answer formats are good for communicating facts and addressing worries. Personal stories are important for making information relevant.

Peer-to-peer communication is powerful, and many organisations offer online support networks for young people. You may choose to use social media, which is simply part of everyday life for most teenagers in the UK.

For young people with a long-term condition, [the chance to meet peers](#) in real life is highly valued. Could you run camps, workshops or other events? Young people can take a very active role in creating and disseminating health information. They are great at promotion and publicity.



Epilepsy space



Epilepsy Space is a mobile-friendly website created by young people for young people to help them manage their epilepsy. It is full of information, tips, and stories from young people sharing their experience.

Young people with epilepsy can learn more about their condition, share with others, and increase their confidence to live well with the condition.

Topics include independence, medical issues and sex, hormones and parenthood.

All the content has been reviewed by epilepsy specialist nurses and young people.

Chapter four: Creating high-quality information

Digital animation to enhance child development

Case study | Digital Mentality

Developing core emotional wellbeing and communication skills in early childhood is known to be fundamental to living healthy and happy lives.

However, there is a lack of resources specifically designed for young children that have a joined up approach including the children, their parents and carers, and education providers.

Wanting to address this gap, the team developing the resource joined forces with experts in animation design. The team included specialist charities and a university research department. Together they had experience working with children and families with special educational needs, in Child and Adolescent Mental Health

Services and as parents and family members. Underpinned by clinical science, and with storyboards designed in collaboration with families, the resulting animations take a fun and adventurous view of childhood challenges. Children join Embers the Dragon and his friends in learning new skills for everyday life.

The animations are coupled with downloadable resources to be used with parents and teachers.

The Embers the Dragon Emotional Wellbeing module is available through schools and services.

See the resource at embersthedragon.co.uk



Tip: 'The strength of the programme is in bringing together families and schools to support children and families to feel empowered and supported.'

Chapter four: Creating high-quality information

Accessibility

It is important to think of all your potential users from the outset. For example, taking into account the needs of children and young people with Special Educational Needs and Disability (SEND) challenges such as hearing loss or impaired vision. Children and young people on the autistic spectrum also have particular accessibility needs, as demonstrated in the Ambitious about Autism case study on page 24.

Children and young people have the right to be meaningfully involved in all decisions that affect them but, for many reasons, it may be difficult to engage with them during healthcare appointments. Providing accessible information in printed format or other media is a key way to involve children and young people in their own care.



The Equality Act

The Equality Act (2010) makes clear that it is unlawful to discriminate against a disabled person, for instance by offering a service that is not as good as that offered to a non-disabled person. It is good practice and the responsibility of each organisation to take reasonable steps to provide information in an accessible format. For example, including visual communications, providing Braille and large print versions and, when using video, to arrange subtitles and/or British Sign Language (BSL) translation.

For some children with disabilities, the scope for making decisions may be severely limited. At the same time, they are likely to experience more medical interventions than other children.

Chapter four: Creating high-quality information

Make provision for audiences with:

- **Hearing loss:** Include visual communications and, when using videos, arrange subtitles and/or British Sign Language (BSL) translation. [GOV.UK](#), [NHS Accessible Information Standard](#) and the [National Deaf Children's Society](#) publish guidelines.
- **Visual impairment:** Remember to budget for accessible options such as large print, audio or Braille. [GOV.UK](#) and the [NHS Accessible Information Standard](#) publish guidelines.
- **Speech, language and communication needs:** The children's communication charity, iCan, offers a wealth of information and advice at: [ican.org.uk](#). So does the disability charity, Scope: [scope.org.uk](#)

- **Learning disabilities:** Children and young people with learning disabilities will vary in their needs. Some will require dedicated one-to-one communication, while others can access information through pictures and diagrams. For some examples, have a look at [easyhealth.org.uk](#). There are also guidelines from GOV.UK and Mencap.

Generally, the best information solutions for all children and young people will be those that are most inclusive.

NHS Accessible Information Standard

This guidance on accessibility in health and social care settings came into force in August 2016. It sets out a consistent approach to meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss.

You can find the Standard and supporting documentation at [england.nhs.uk](#)

Tip: Using symbols can make your material more accessible to people who find it difficult to read text. Visit Widgit at: [widgit.com](#)

Chapter four: Creating high-quality information

Languages other than English

A growing proportion of children in the UK have a first language other than English. In 2019, according to the [Department for Education](#), this applied to nearly 17% of children in secondary schools, about 20% in primary schools and nearly 15% in special schools. Therefore, it is increasingly important to ensure your information is accessible to this group.

Depending on the geographic range of your information and services, it may be particularly important to try to meet the language and communication needs of Welsh speakers. As Public Health Wales says: "Many people can only communicate and participate in their services as equal partners effectively through the medium of Welsh." As with other languages, best

practice is to produce bilingual editions of resources so that English-speakers can understand and help to disseminate the information.

Using clear, plain language is helpful when your audience does not have English as a first language. It also aids people with communication needs, and improves understanding for everyone using your material. The Plain English Campaign offers free guides at plainenglish.co.uk.

If you are thinking about producing any translations, involve young people from relevant communities early on rather than seeing this as an add-on at the end of the process.



Chapter four: Creating high-quality information

Cultural diversity

It is common to worry about 'getting it right' when it comes to cultural diversity, but there are no right or wrong answers. People do not fit into homogeneous groups – every individual is different. What matters is intent along with an effort to understand.

We all view the world through our own experiences, perceptions and assumptions. Even people with similar backgrounds might see a subject very differently. Having someone to challenge your approach is one of the benefits of working in a team.

At every stage of your project, remember to check out your own perspective. It helps to write down your personal views on issues like gender, sexual orientation, race, social class, age and even politics.

Ask yourself how others' views might differ and how this could be addressed in the work. It is important to think broadly and do your best to ensure the information can reach a wide range of children and young people.



Connecting with traumatised children and young people

Some children and young people struggle to place confidence in professionals. They may have been let down in the past or perceive professionals as responsible for some of the trauma they have experienced.

There are often complex root causes behind this including disordered attachment, emotional and physical trauma.

An interaction most may see as neutral or therapeutic may not be taken that way. Even a simple lanyard can carry negative associations for children and young people who have had previous bad experience with social workers, police, teachers and so on.

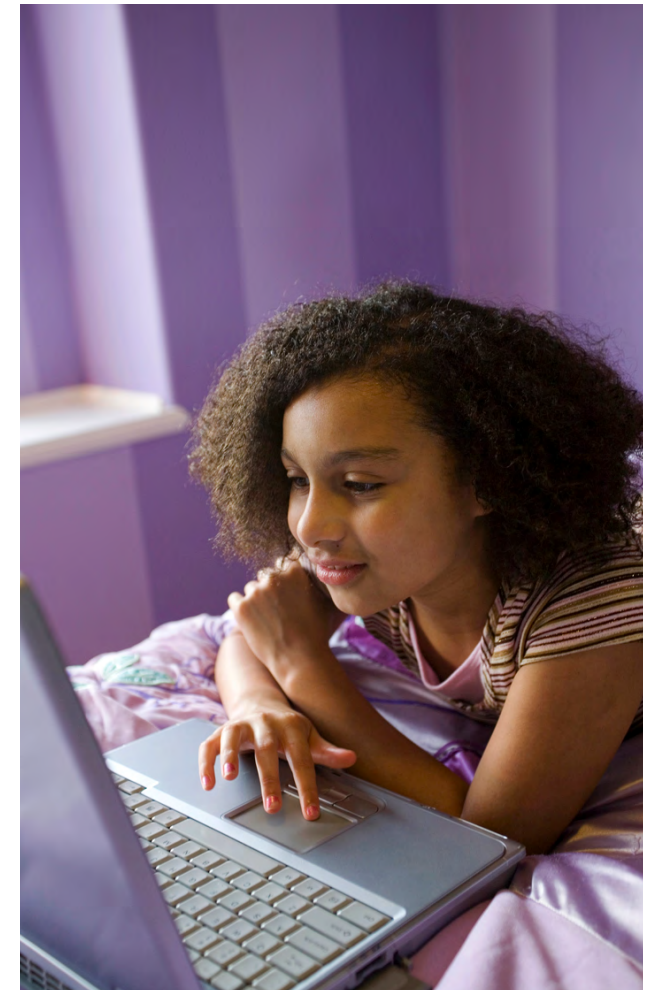
Chapter four: Creating high-quality information

If your target audience may be affected by some of the issues above, here are some key points to keep in mind when producing health information resources. Although they do not differ widely to ideas mentioned elsewhere in this booklet, they may be particular important to children and young people affected by trauma and disaffection with authority, including health services.

- Keep the important information clear and to the point.
- Think about why this young person needs to know the information and present it accordingly.
- Consider novel platforms for information sharing such as Instagram, Snapchat and YouTube. TikTok may be suitable for younger people. Catch 22 and Social Switch (see page 42) provide a wealth

of information about children and young people and social media/internet access.

- Respect the maturity-beyond-years some children and young people may carry, but also realise some might nevertheless struggle to read large blocks of text or information presented formally.
- Consider novel means of presenting the information such as a credit card-sized leaflet or a plastic card wallet.
- Who might people in your target audience turn to for advice or further information? Are there local advocates or youth services they can approach?



Chapter four: Creating high-quality information

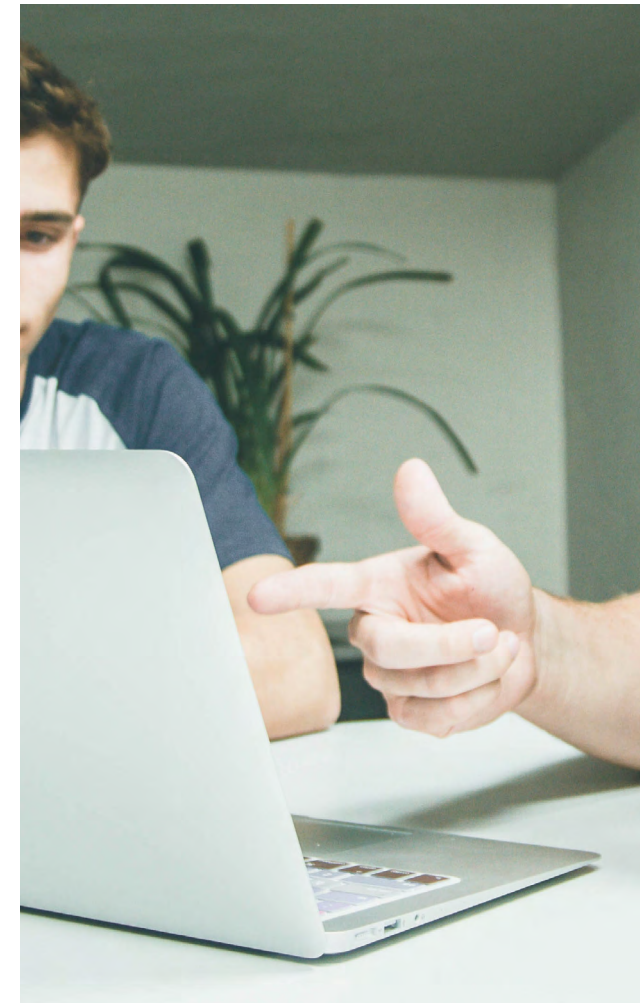
Interpersonal skills

Interpersonal skills are always important when relaying health information. But never more so than when trying to support traumatised and disaffected children and young people.

- **Try to build rapport** and show an interest beyond merely relaying information. Be the first person to challenges their perception of professionals.
- **Discuss information in private** allowing space for questions to be asked. They have the right to be able to talk away from parents and other people.
- **Be flexible** about how they might want to access more information.
- **Try to anticipate their anxieties.** For instance, if they are expecting a phone call from another team, give them a

number to call if they do not hear within an agreed time frame. If they have a limited supply of medication, provide clear instructions on how to get more.

- **Don't make promises that can't be kept** – this includes setting time frames for treatment or recovery. If a young person needs to come back to a clinic or GP on a certain time, set a date, and set an alternative date.
- **Avoid using ambiguous phrases** like 'a few days' or 'reasonable time' – be specific. If traumatised young people feel let down they will disengage.
- **Think outside the box.** If there is a good resource available, can you type the address into their phone browser? Or could you have pre-made QR codes they can photograph during your consultation?



Chapter four: Creating high-quality information

Your Stance Zero Responder Workshop | Case study | Barts Health NHS Foundation Trust

Trends in young people attending a London hospital emergency department with knife wounds led to the development of a teaching outreach programme.

Doctors and nurses in the department noticed that some young people would present several times, frequently with increasingly severe injuries.

In response the team set up a teaching outreach programme to provide first aid training to young people deemed to be at risk of injury or criminal exploitation. The programme was non-judgemental and positive, focusing on delivering skills training.

The team worked alongside established networks and community organisations that were trusted by young people.

The short, practical sessions were delivered by volunteers, including young people. They focus on teaching what to do if someone is injured, especially from stabbing.

Conversations are open and non-judgemental, and young people are encouraged to question and criticise the facilitators. Feedback from young people is taken on board dynamically, and content is often modified mid-session to reflect the interests of the particular group of young people.

As the programme has evolved the project now includes street outreach sessions with local youth workers and in young offenders' institutes. Session facilitators receive information in advance about participants' previous experiences of injury, criminality or trauma. In this way sessions can be tailored, in particular so as not to trigger trauma.

Tip: 'The success of the programme is built on each session being led by the interests and experience of young people, with an overarching goal of sharing life-saving first aider skills.'

Chapter four: Creating high-quality information

Information for young carers

In England, there are [at least 166,000 young carers](#) aged five to 17 looking after parents or family members with disabilities, physical or mental illness, or substance abuse problems. These were the young people officially recognised during the last census, and there are probably many more.

When someone in the family has a health condition, children and young people need information so they can understand what is going on and find answers to the questions that are worrying them. Yet young carers say this does not happen very often.

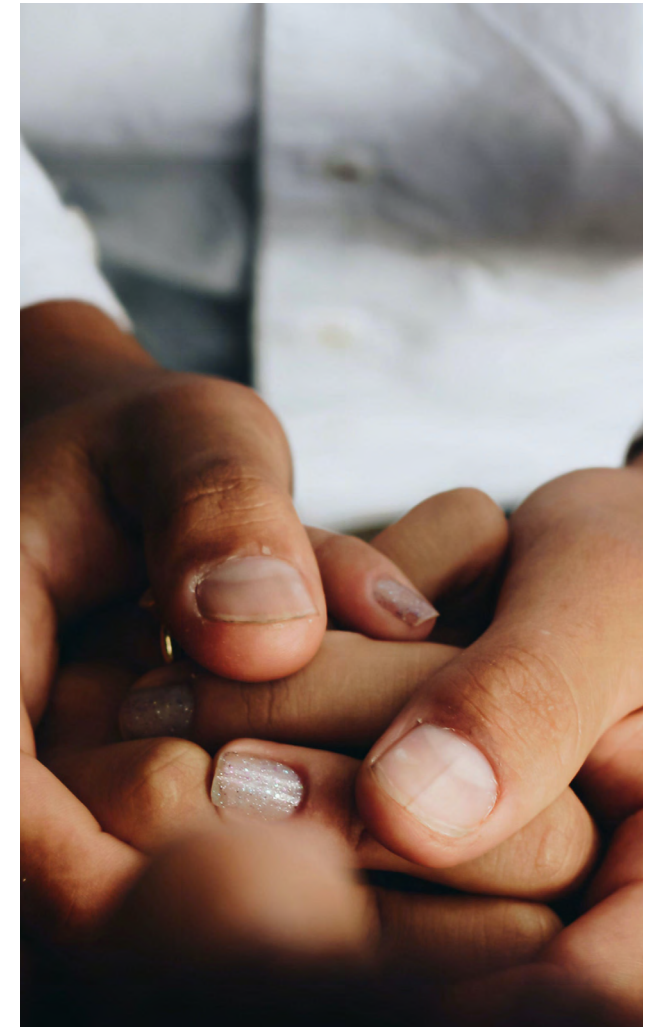
Young carers have high levels of poor physical and mental health themselves, and need more support to look after their own wellbeing. The most effective way to reach and help young carers is through front line healthcare

professionals on the ground. Young carers need information that is tailored to their age and level of understanding. There is no one size that fits all. It is about asking relevant questions and answering in an appropriate manner. Young carers do not just need to be given information – they need someone to talk to.

More about young carers

You can find a comprehensive library of Children's Society resources for professionals and young carers at: www.youngcarer.com

The Children's Society consults intensively with young carers and involves them in delivering support work.



Chapter four: Creating high-quality information

Choosing your format

Once you understand your audience and their needs, you can decide on the best format. It will depend on:

- The topic.
- The age group.
- Other audience characteristics such as accessibility needs, internet access or literacy skills.
- The skills and resources available for your project.
- Your budget.

You may choose to use more than one approach, which will help ensure accessibility, and accommodate a wider range of learning styles and segmented audiences. The tables on the following pages look at some of the options and summarises their pros and cons.

Picture book or story book



Strengths

- A familiar and friendly format for children under seven.
- Can be produced in print or e-book form, with activities built in.
- Can be shared with a parent, carer or professional.

Limitations

- Requires specialist artwork and writing skills.
- Can be expensive to produce.
- Will only cover small amounts of information.
- May be too expensive for some families if not provided by healthcare professionals or charities.

Leaflets



Strengths

- Portable – can be used in clinics, schools, libraries.
- Concise and focused.
- Can be print or digital.

Limitations

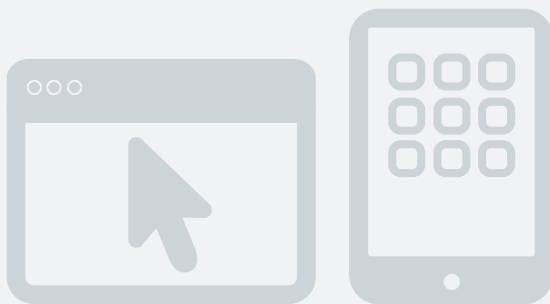
- Difficult to personalise.
- Limited information that cannot be questioned.
- Young people sometimes view traditional formats as boring, although a leaflet and a prompt sheet with links may be more acceptable to many.
- Potential accessibility issues for people with low literacy, a first language other than English or with visual impairment.

Chapter four: Creating high-quality information

Websites and apps

Strengths

- You may be able to build on the existing infrastructure of your organisation.
- Multimedia resources can be provided, increasing accessibility and accommodating different learning styles.
- Opportunities for children and young people to contribute, ask questions and stay involved.
- Personalisation and interactivity.
- The majority of young people own a smartphone. Many younger children are allowed to use a parent's smartphone with supervision.



Limitations

- Children and young people may find it hard to locate your website, or not consider looking for it. Investment needed in search engine optimisation.
- While internet use is very widespread, not everyone has access, especially in lower-income households.
- Apps typically collect data from users. This may not be appropriate for your audience.
- Any website version must also be mobile optimised so that it works on smartphones.
- Materials accessible via an app may be limited by the device (a specific tablet, smartphone, desktop computer).
- Text may need to be separately adapted for print and screen. Generally people read differently on a screen.
- Can be an expensive option.

Audio



Strengths

- Audio downloads are familiar formats for most young people. Podcasts are becoming increasingly popular, especially with teenagers.
- Can be used alone or shared with others.
- Good accessibility for younger children, people with visual impairment or lower literacy; can be recorded in different languages.
- Can be simple and affordable to produce.

Limitations

- Some people will not have access to the technology needed.
- No scope for illustrations.
- An alternative needed for people with hearing loss.

Chapter four: Creating high-quality information

Video, films and animations

Strengths

- Popular format with all age groups.
- Effective way to introduce new environments or explain a procedure or process, even to young children or those with low literacy.
- Can be helpful for people who do not have English as a first language.
- Animations can clearly explain clinical procedures and how the body works.
- Can be adapted for accessibility with subtitles, British Sign Language interpretation or non-English voiceover.

Limitations

- Can be expensive to produce, including alternatives for people with visual impairment or hearing loss.
- Some people may not have access to the technology for viewing.
- You will need written permission from everyone appearing in the video.



Comics



Strengths

- Enhances understanding and improves recall.
- Helpful for people with low literacy levels or whose first language is not English.
- Can address social or emotional issues through storytelling.

Limitations

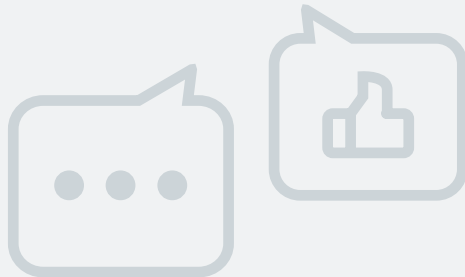
- Some people might find the format patronising or off-putting.
- Inaccessible for people with a visual impairment.
- Getting the artwork and tone right needs specialist skills.
- Can be an expensive option.

Chapter four: Creating high-quality information

Social networking and online communities

Strengths

- Very accessible and familiar format for most young people.
- Can be a relatively inexpensive as much of the support and information comes from the users themselves.
- Opens the door for involvement, content is relevant to the audience, gives young people a voice.



Limitations

- May need a moderator and strict controls to ensure safeguarding, confidentiality and compliance with data protection laws.
- A high level of participation is needed to make it work.
- Some young people do not want to access information this way, and are concerned about privacy and security.
- It can be challenging to strike the right balance between young people setting the agenda and getting important messages across with accuracy.

Tools for social marketing

The National Social Marketing Centre provides an opportunity to share research findings. They also offer advice, tools and case studies that might be helpful in planning your campaign.

Visit: thensmc.com

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References

GOV.UK. 2020.
The national curriculum: Overview.
Accessed: www.gov.uk March 2020.

GOV.UK. 2020.
Early years foundation stage.
Accessed: www.gov.uk March 2020.

Ofcom. 2020.
Children and parents: media use and attitudes report 2019.
Accessed: www.ofcom.org.uk March 2020.

GOV.UK. 2018.
Teacher Assessment frameworks at the end of key stage 1.
Accessed: www.gov.uk March 2020.

Patient Information Forum. 2020.
Accessed pifonline.org.uk November 2020.

GOV.UK. 2020.
The national curriculum: Overview.
Accessed: www.gov.uk March 2020.

Office for National Statistics. 2018.
Internet users, UK: 2018.
Accessed: www.ons.gov.uk March 2020.

GOV.UK. 2020.
The national curriculum: Key stages 3 and 4.
Accessed: www.gov.uk March 2020.

Ofcom. 2019.
Why children spend time online.
Accessed: www.ofcom.org.uk March 2020.

The Guardian. 2020.
Most children own mobile phone by age of seven, study finds. Report of Childwise study.
Accessed: www.theguardian.com March 2020.

Public Health Wales.
Welsh Language.
Accessed: phw.nhs.wales September 2020.

Crohn's and Colitis Foundation. 2018.
Join the community: Camp Oasis.
Accessed: www.justlikemeibd.org March 2020.

NHS England. 2016.
Accessible Information Standard: Different types of accessible information and communication support and who may need them.
Accessed: www.england.nhs.uk March 2020.

GOV.UK. 2016.
Making written information easier to understand for people with learning disabilities.
Accessed: www.gov.uk March 2020.

Department for Education. 2019.
Schools, pupils and their characteristics.
Accessed: www.gov.uk March 2020.

Department for Education. 2016.
The lives of young carers in England.
Accessed: www.gov.uk March 2020.

Chapter four: Creating high-quality information

Bibliography

Children's Society. 2013.
Hidden from view: The experiences of young carers in England.
Accessed: www.childrenssociety.org.uk March 2020.

Department for Work and Pensions and The Office for Disability Issues. 2018.
Accessible Communication Formats.
Accessed: www.gov.uk March 2020.

Dickins, M. 2011.
Listening as a way of life - Listening to young disabled children. Published by the National Children's Bureau.
Accessed: www.ncb.org.uk March 2020.

Engel K. 2019.
How to build a kid-friendly website.
Accessed: www.whoishostingthis.com March 2020.

Green M, Myers, K. Graphic medicine: use of comics in medical education and patient care. BMJ, 2010. 340:c863.

Grimes SM, Fields DA. 2012.
Kids online: A new research agenda for understanding social networking forums.
Accessed: www.joanganzcooneycenter.org March 2020.

Hamadache G. 2018.
Freedom-To-Be Residential Camp Evaluation Report 2018. Published by the Children's HIV Association.
Accessed: www.chiva.org.uk March 2020.

Holloway D, Green L, Livingstone S. 2013.
Zero to eight. Young children and their internet use. LSE, London: EU Kids Online.
Accessed: <https://eprints.lse.ac.uk> March 2020.

Jochmann-Mannak H, Lentz L, Huibers T et al.
Three types of children's informational web sites: An inventory of design conventions. Technical Communication, 2012. 59(4): 302-323.
Accessed: research.utwente.nl March 2020.

Livingstone S, Haddon L, Görzig A et al. 2011. Risks and safety on the internet: The perspective of European children. Full Findings. LSE, London: EU Kids Online.
Accessed: <https://eprints.lse.ac.uk/> March 2020.

McNicol S.
The potential of educational comics as a health information medium.
Health Info Libr J, 2017. Mar; 34(1): 20–31.

Mencap. 2002.
Am I Making Myself Clear?
Accessed: accessibleinfo.co.uk March 2020.

National Deaf Children's Society. 2013.
How you can make your resources accessible to deaf children and young people.
Accessed: www.ndcs.org.uk March 2020.

Sherwin K, Nielsen J. 2019.
Children's UX: Usability Issues in Designing for Young People.
Accessed: www.nngroup.com March 2020.

Smashingmagazine.com. 2011.
Best practice for web design for kids.
Accessed: www.smashingmagazine.com March 2020.

Takeuchi L, Stevens R et al. 2011.
The new coviewing: designing for learning through joint media engagement. Published by The Joan Ganz Cooney Center at Sesame Workshop and LIFE Center.
Accessed: www.joanganzcooneycenter.org March 2020.

Where to learn more – contacts and resources

Key points

- Use this section to explore any of the topics from the guide in more detail.
- There are links to more sources on health and education policy.
- You will also find resources about involving children and young people, and examples of best practice.
- There are links to more resources on disabilities, equality and diversity, using digital media, and social care best practice.
- When you are ready to create your health information, there are contacts to help you find suppliers and resources for: children's health and medical writing; graphic design; medical illustration; translation; website and games design.
- In addition to the case studies in this guide, there are more examples showing how successful health information can work for children and young people.

Producing health information for children and young people can be a daunting responsibility. However, there are many resources to help you understand their needs and produce high-quality results.

Consult and involve professionals, and look at as many examples of good practice as you can. This section of the guide provides some ideas about where to explore the field, learn more and find expert support and input for your projects.

Health policy, practice and evidence

- **Department of Health (England)** For latest policy and guidance. [gov.uk](https://www.gov.uk)
- **Department of Health, Social Services and Public Safety (Northern Ireland)** For latest policy and guidance. dhsspsni.gov.uk
- **Health in Wales** Gateway to health policy, guidance and more. wales.nhs.uk
- **NHS digital information pages** Check that your advice aligns with NHS information for the public. nhs.uk
- **NHS evidence search** (Hosted by NICE, includes British National Formulary for Children). Find high quality research, guidelines and academic sources to inform your content. evidence.nhs.uk
- **NHS England** Sets out the roadmap for personalised care as standard by 2023-24 england.nhs.uk/personalisedcare
- **Scotland's Health on the Web** Gateway to health policy, guidance and more. scot.nhs.uk
- **University of Oxford, Centre for Evidence-Based Medicine** Find information, resources and tools to help you find, understand and assess medical research reports. cebmn.net

Chapter five: Where to learn more – contacts and resources

Education and learning

- **BBC Bitesize**
Get in touch with education and find a wealth of high-quality resources.
bbc.co.uk/bitesize
- **Department for Education**
(England) Ensure your project is a good fit with education policy and the national curriculum. You'll also find guidance and reports. gov.uk/dfes
- **Department of Education Northern Ireland**
Education policy, reports, guidance and the curriculum. deni.gov.uk
- **Education Resources Information Center**
A gateway to extensive academic research on childhood education worldwide, including health. eric.ed.gov
- **Education Scotland**
Education policy, reports, guidance and the curriculum. education.gov.scot
- **Learning Wales**
Education policy, reports, guidance and the curriculum.
gov.wales/education-skills
- **Office of the Children's Commissioner (England)**
childrenscommissioner.gov.uk
- **Children's Commissioner for Wales**
childcom.org.uk
- **Children and Young People's Commissioner Scotland** sccyp.org.uk
- **Northern Ireland Commissioner for Children and Young People**
niccy.org

Chapter five: Where to learn more – contacts and resources

Creating health information

- **Chartered Society of Designers**
Find a designer for your project, and learn more about the world of design. csd.org.uk
- **Chartered Institute of Linguists**
Find a translator for your material. iol.org.uk
- **Computer Weekly**
Search for suppliers and get quotes for graphic design and video production. There are also buyer's guides to download. computerweekly.com
- **Guild of Health Writers**
Find a specialist writer or editor. Send an email to the administrator if you are looking for a freelancer. healthwriters.com
- **Information Standard**
NHS England Quality Standard for health information england.nhs.uk/tis
- **Institute of Medical Illustrators**
Lists specialists in clinical photography, medical art, illustration, graphic design and video production. imi.org.uk
- **Institute of Translation and Interpreting**
Find a translator for your material. iti.org.uk
- **Medical Artists' Association of Great Britain**
Find an illustrator for your project. maa.org.uk
- **Medical Journalists' Association**
Send an email to the Secretary if you are looking for a medical writer. mjauk.org
- **The Society of Authors: Children's Writers and Illustrators Group; Medical Writers Group; Translators Association**
Find an expert to write or translate your material. societyofauthors.org

Chapter five: Where to learn more – contacts and resources

Involving children and young people

- **Council for Disabled Children**
Many resources and ideas, plus an extensive programme of involvement. councilfordisabledchildren.org.uk
- **National Children's Bureau**
Useful resources including the Listening as a way of life series. ncb.org.uk
- **National Youth Agency**
Hear by Right helps organisations follow best practice on participation of children and young people. nya.org.uk
- **Rich E et al, 2020. The Digital Health Generation:** the impact of "healthy lifestyle" technologies on young people's learning, identities and health practices. University of Bath, Bath, UK. static1.squarespace.com
- **NSPCC**
A good starting point for information on safeguarding (child protection). nspcc.org.uk
- **Participation Works Partnership**
Find training, resources and latest news. theparticipationworks.org.uk
- **Royal College of Paediatrics and Child Health**
Resources and guidance on child health, safeguarding, and involvement. rcpch.ac.uk
- **Equality and Human Rights Commission**
Learn about your organisation's legal obligations to make health information accessible to all. equalityhumanrights.com
- **Communicating health information**
RNID (formerly Action on Hearing Loss) Accessibility guidelines. rnid.org.uk
- **Equally Ours** (formerly the Equality and Diversity Forum)
Information, resources, training and guidance to ensure your approach is inclusive. equallyours.org.uk
- **Early Years Learning Alliance** (formerly Preschool Learning Alliance)
Gain insights into early years education eyalliance.org.uk
- **Fred Rogers Workshop**
Based in the US, this website provides a wealth of information and resources on best practice in digital and multi-media education for children. www.fredrogerscenter.org

Chapter five: Where to learn more – contacts and resources

- **Joan Ganz Cooney Center and the Sesame Street Workshop (US)**
A great source of information and research on digital media and early childhood education.
joanganzcooneycenter.org
- **RNIB**
Accessibility guidelines. rnib.org.uk
- **Social Care Institute for Excellence**
Find reliable guidance on communicating with various groups, including children and young people. scie.org.uk

Further inspiring examples

In addition to the case studies in this guide, these resources show how successful health information can work well for children and young people.

- **British Heart Foundation**
www.bhf.org.uk
- **Crohn's in Childhood Research Association**
www.cicra.org
- **CLIC Sargent**
www.clicsargent.org.uk
- **Great Ormond Street Hospital**
www.gosh.nhs.uk
- **Macmillan Cancer Support**
(see cancer info for teens and young adults)
www.macmillan.org.uk
- **National Deaf Children's Society**
www.buzz.org.uk
- **Teenage Cancer Trust**
www.teenagecancertrust.org
- **Teenage Health Freak**
www.childrenshealthscotland.org
- **Young Minds**
www.youngminds.org.uk

Feedback

Feedback

We welcome your comments and suggestions about this guide. By giving us constructive feedback you can help us to produce higher quality and more relevant information in the future. If you would like to give your feedback, you can either go to the PIF website, pifonline.org.uk, and complete the feedback form there or contact the PIF administrator admin@pifonline.org.uk with your comments.

About the Patient Information Forum

PIF represents more than 1,000 members in 300 cross-sector organisations. These include national charities, the NHS, commercial, government, freelance and academic sectors. We use the insight and support of our membership to lobby governments in support of our vision.

Our expert guidance helps our members to provide high-quality, clearly communicated, evidence-based healthcare information. The aim is to empower people to make informed decisions about their health and improve outcomes.

This supports an improved healthcare experience for patients and the public.

Health information is a therapy in its own right and should be accessible to all.

To join or find out more about PIF visit pifonline.org.uk or contact admin@pifonline.org.uk.

Join us

PIF is the independent UK membership body for people working in health information and support. We operate the PIF TICK, the UK-wide quality mark for health information.

Our vision

Everyone has access to personalised health information and support to enable them to make informed decisions about their health, wellbeing and care.

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