New 2014 edition

Patient Information Forum

# Guide to Producing Health Information for Children and Young People




**Patient Information Forum**
*For Professionals Working in Consumer Health Information*

## The Patient Information Forum

The Patient Information Forum (PiF) is the organisation for professionals working in health information.

We campaign to ensure that consumer health information is central to high quality, patient centred care and we help providers to develop high quality information for their patients and the public. PiF is a non-profit, independent organisation with members in all healthcare sectors and in every country in the UK.

PiF provides a range of services for its members and the wider consumer health information community. These include a website, weekly email newsletter, events, guides, query service and online specialist groups and a regional coordinator network.

This guide is one of a series and is part of an ongoing programme of work to develop practice based guidance, supported by evidence, which helps organisations to provide the best information for their service users.

To find out more about PiF, our work and our members, or to join go to: www.pifonline.org.uk or contact admin@pifonline.org.uk



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# Welcome



When it comes to our health and wellbeing, we all need and want high quality, reliable information. Experience as a children's nurse has shown me that having access to sensitive, accurate, well-timed information makes the world of difference to physical and emotional wellbeing at any age. It's so important to take the time to listen, talk to the child or young person as well as the parent and, for our younger patients, communicate through play.

Health issues can be scary and information is critical. Whether we are supporting a child being admitted to hospital for a routine procedure, a young person with mental health concerns, or a child who is worried about a family member, information that is accurate and understandable is essential. The same is true for health promotion interventions like the flu immunisation programme. Children and young people are thirsty for knowledge, and as professionals we have a duty to identify and meet their needs, ensuring their health care journey is as informed as possible.

We all love a story; whether it's told through a traditional storybook, interactive play, an educational game, a bright leaflet or a website, it takes us on a journey to being more informed and empowered.

Social media offers exciting new opportunities too, and what is critical as we move forward is identifying good, safe practice so we can maximise the positive benefits this communication medium can offer.

This rich resource gathers the evidence, highlights the challenges, inspires us with case studies and helpfully provides quick tips on creating high quality, developmentally appropriate information. So what does good health information for children and young people look like? Dip in and find out! Enjoy!

***Kath Evans***
*Head of Patient Experience - Maternity, Newborn, Children and Young People*
NHS England

## About this guide

If you are involved in creating health information for children and young people, then this guide is for you.

Inside, you'll find practical information to help you produce results that are of high quality, appropriate and effective. We've brought together the experience of health information providers in the NHS, voluntary and private sectors, and there are many case studies that are examples of good practice.

Within this introduction there is a summary of all the guide's key points, which can serve as a quick reference.

We are keen to hear your feedback, so please send any comments to:

admin@pifonline.org.uk

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**Chapter 1 establishes why the right information matters**, explaining why special information for this audience is needed and why it is important. There are also practical tips on writing for children, with suggestions you can put into practice right away, including the factors you might need to consider in preparing information for children of different ages and with different needs.

**Chapter 2 looks at involving children and young people** in the development and creation of information, explaining the rationale and how to go about it. You'll hear about the practicalities and how to make involvement meaningful and inclusive.

**Chapter 3 is about communicating with children and young people**, including when and how to give information, and taking a holistic approach. It also talks about different scenarios such as patient consultations, family-centred communication, peer support, providing information in schools, and independent information seeking online.

**Chapter 4 looks at producing information materials for children and young people**, examining the needs of different audiences and age groups, and the pros and cons of different formats. It also discusses accessibility for audiences with a disability or special communication needs, or with a first language other than English. There is a reminder about the importance of information and support for young carers.

**Chapter 5 lists useful resources**, organisations and contacts to help you research and understand the information needs and learning styles of children and young people, and produce engaging information that meets their needs.

Each chapter is referenced, so you can follow up in depth and learn more about the topics that are most important to you.

For supporting references, please see the full text of each chapter.

## Chapter One: Why the right information matters

- Children and young people have a right to seek information and speak up about all matters that affect them, including their own health and wellbeing.
- They also need information that is given in a way they can understand, so they can participate in decisions about care, as appropriate to their age and maturity. This is vital because young people, rather than their parents, may be the ones to give consent for examinations, tests and treatments.
- There is a huge body of health information for children and young people but it varies in terms of quality and accessibility. The evidence base is patchy and some topics have been researched more than others.
- Accessibility is vital, so take into account the diversity of your audience. Consider language, culture, social needs, disability, sexual orientation, gender and literacy, as well as age and level of development.
- Golden rules when writing for children:
  1. Keep sentences short and order them logically.
  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 - break them up.
  5. Present facts in a short and punchy way, such as 'Did you Know?'
  6. Provide ways to recap and check understanding.
- Look at books, websites, comics and magazines that are popular with your target audience, to learn what works.
- Writing about subjects that may be delicate, frightening, or potentially upsetting takes particular sensitivity.



For supporting references, please see the full text of each chapter.

## Chapter Two: Involving children and young people

- Listening to patients is good professional practice, 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 outset means your information will be relevant and well targeted.
- The consultation experience also benefits children, because they gain confidence and learn. They also feel valued and learn that their opinions matter.
- Consulting children and young people is essential if you are Information Standard certified.
- Children and young people should be involved at all stages, from initial development to evaluation.
- From the start, seek to understand your audience broadly and take steps to make involvement as representative and inclusive as you can.
- Take special care to involve children and young people who might be harder to identify and engage, so their voices are heard too.
- Everyone who has contact with children has a duty of care, so your organisation must have a clear safeguarding policy.
- Activities for small groups work well, but not for everyone. Consider different preferences, and try to offer more than one format.
- Make activities fun. Art, music and drama encourage expression. Provide refreshments and offer a chance to socialise.
- An independent facilitator is recommended. Children and young people are also good facilitators.
- Cover expenses so everyone can afford to take part.
- Thank your participants with a letter, prize or certificate, and share the end result.



For supporting references, please see the full text of each chapter.

## Chapter Three: Communicating health information

- Information is just one part of the communication process, which may also involve interaction with health professionals, parents and family, peers and teachers.
- When communicating with children and young people, establish 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 also impart health information, and 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 digital media, young people do not consistently use the internet when seeking health information. Online information aimed at young people is also variable in terms of quality and accessibility. Children may not have the skills to assess the reliability of information they find.
- Because it is such a new format, there is little evidence about the effectiveness of mobile apps. Some research shows that young adults value accuracy, security and ease of use.
- Whatever format you choose, when children or young people are likely to be using the resource independently, make sure to include clear signposting to more information, advice and support.



For supporting references, please see the full text of each chapter.

## Chapter Four: Creating high quality health information

- The first step is to assess the need for new information. Make sure the purpose is clear. Ask whether you can update or build on existing resources, and check that you are not duplicating information that is already available from other good sources.
- Run through a planning checklist to 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 you choose digital media, create a resource that can be shared by parent and child.
- For children aged five to seven, use short bursts of information and a storytelling approach. By this age, nearly six in ten 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 eight to 11 like the question and answer format. Look at popular books, games, websites and apps to see what works well. Children are still building their confidence as internet users.
- Don't forget more traditional media, because one in 14 children aged 5 to 15 do not access the internet anywhere. Not all families have internet access at home. Some children prefer traditional formats.
- By secondary school, digital formats like videos, games and smartphone apps are familiar and popular. Most teenagers use social networking, but strict controls are needed to protect them. For young people with a long-term condition, the chance to meet peers 'in real life' is also highly valued.
- Remember the need to make your material accessible to individuals with hearing loss, visual impairment, and special communication needs.
- Many children have a first language other than English. Use plain language, consider accessible formats, and plan for translation if needed.
- Take cultural factors into account. This is about more than ethnicity or language, which are only two facets of an individual's perspective. Consider parents and families in this context,

For supporting references, please see the full text of each chapter.

## Chapter Four: Creating high quality health information

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. These young people need a lot of support and the best way to reach them is through professionals who can provide it.
- 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 wider range of learning styles.
- Some options include leaflets, comics, picture books or storybooks, audio recordings, videos, websites, social networking, games, apps and help lines.

## Chapter Five: Where to learn more

- Refer to this section if you want 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're 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.

## The right to understand

Children and young people have the right to seek information and speak up about all matters that affect them, including their own health and wellbeing.

They also need information that enables them to participate in decisions about care, as appropriate to their age and maturity. For example, professional guidance for doctors says they must provide age-appropriate information about a child or young person's condition, tests and treatment options. They should also explain who will be involved in the patient's care, and their right to a second opinion.

Information is vital in this context because young people, rather than their parents, may be the ones to give consent for examinations, tests and treatment. Many children and young people are competent to make their own decisions. The legal position concerning consent to treatment is different than for adults, and autonomy for young people increases with age and their capacity to understand the decision and its consequences. Even for younger children, health professionals will seek to gain their agreement as far as possible.

Children's questions about their care 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. It is important not to patronise, to take children seriously and to be honest if you do not know something. When asked, many children stress that they want to know the truth.

However, bear in mind that intellectual ability to understand a condition is not the same thing as emotional readiness to cope with its impact. There is information on page **17**, on writing about sensitive or frightening subjects.

Like anyone, children and young people need accessible and reliable information to find services and support their decision-making. In a consultation for England's Chief Medical Officer, young people gave a strong message: they want and need such information. But too often, they can't find it or it is not there.

### Giving children a voice

Children and young people face barriers when they want to express unhappiness with a service, so the Children's Commissioner for England has set out principles to underpin a child-friendly complaints process.

The right to have an informed voice in their own health care is an important theme that is highlighted across a wide and growing range of government policies for children and young people, which are explained in more detail in **Chapter 2**. It's useful to understand this background, because it opens doors if your work helps to meet policy goals. There might be scope for partnerships and it might support your case for funding.

## What works?

While there is a lot of health information out there for children and young people, it's not always easy to know what works. This is because the evidence base is still evolving and the research we do have is not always consistent.

The idea that children have some autonomy, and are entitled to information in their own right (instead of solely through their parents or guardians) is relatively new. So it may take time for the research to catch up with changes in thinking and practice. Therefore, by building strong evaluation into your projects from the start, you can make an essential contribution to the evidence base, while ensuring that your information is meeting the needs of your target audience. Evaluation also allows you to apply this knowledge to updates and future projects.

### Evaluating health information

For practical advice on how to evaluate your project, please visit our website at www.pifonline.org.uk

If you'd like to explore the literature, you'll find a list of interesting studies in the references at the end of this chapter.

We do know that information needs change as a child grows older, and this is especially important for someone who is living with a long-term condition. What worked for a child with asthma at the age of three will not be suitable when they are nine years old.

And don't forget the importance of feelings as well as facts. A young person may understand very well how to manage their diabetes, for example, but they may not follow the management plan for social or emotional reasons.



**Case Study** | My Asthma: Produced by Asthma UK

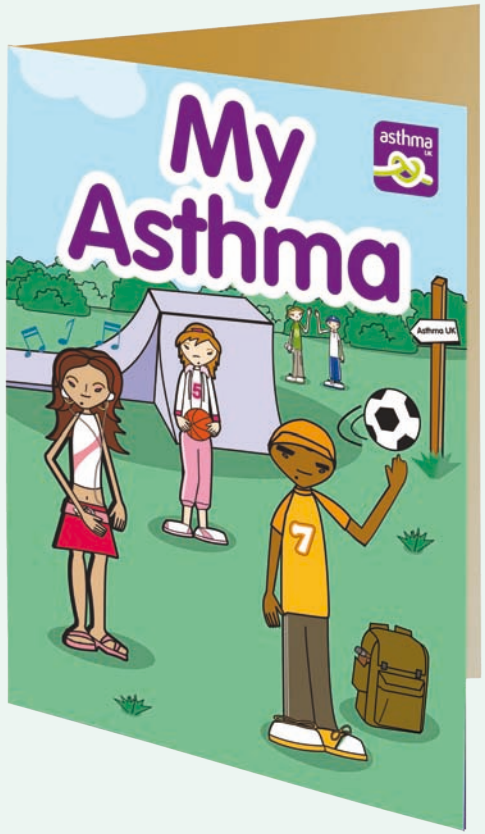
The My Asthma pack was created to help children aged six to 12, and their parents, take a more active role in managing asthma. It also helps the child learn about their condition, and the importance of taking their medicines regularly. The pack includes a wall chart (to monitor symptoms), stickers, an asthma action plan, and information cards for parents, teachers and childminders.

Evaluation was built in from start to finish. Children were consulted during development with help from an expert agency, Education Connections. The pack was piloted in 18 sites, and feedback from children, parents and health professionals was incorporated before launch.

Surveys and qualitative interviews were conducted after the pack had been in use, in an evaluation by the charity's health promotion team. Some 20,000 packs were ordered in 2011, and everyone who requested one was invited to participate.

Health professionals thought the pack was more engaging and effective than materials they had previously used. The majority also thought it improved the child's understanding and adherence to treatment. Most parents thought the resource had improved their child's understanding of asthma, and led to more regular use of their prescribed medicines. Nearly all of the children found the asthma plan easy to understand, and said it helped them learn about what medicines to take.

www.asthma.org.uk



## Accessible information

A study by the NHS National Institute for Health Research found that a huge array of children's health information is available, in the form of leaflets, toys, games, DVDs and websites. Yet these researchers also found that the field is unregulated, quality is variable, resources are not freely accessible to all, and there are significant gaps in provision. So how can we improve the situation?

The National Service Framework (NSF) for Children, Young People and Maternity Services (England) was published in 2004 but still provides useful guidance.

The NSF says that information should be sensitive to developmental, cultural, social and language differences and that specific provision should be made for disabled children with high communication needs. Children and young people should receive information that takes into account their age and development, and reflects their increasing autonomy as they grow up.




Producing that information requires a particular mindset, approach and range of skills, because children are not just small adults - and teenagers and young adults are not just big children. So the way we present information should change at different stages of a young person's development. Bear in mind that past experiences may also shape the way children and young people interpret information.

You can find more detail on how to provide accessible information in **Chapter 4** of this guide.

To put this theory into practice, below you will find some practical tips from Camilla de la Bedoyere, educator and author of more than 250 books for children.

## Writing for children and young people

Children and young people are used to reading texts that contain vocabulary and concepts that 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, they may just skim over it, without asking for clarification.

Writing information for this audience is therefore quite a specialised task, but there are golden rules that will help to get it right.




1. **Keep all sentences short and order them logically.**
   For example, '*You will fall asleep after the injection*' would be better phrased as '*You will have an injection, and then you will fall asleep.*'

2. **Keep the vocabulary simple and explain any new words.**
   Tricky words can be written out properly, and phonetically (using sounds) e.g. '*It is called epilepsy (say: epi-lep-see).*'

3. **Numbers and statistics can be confusing for younger readers.**
   Terms such as '*one-quarter*' or '*60 per cent*' may not mean much to primary school children (and even some older readers), so if data and statistics are important, consider showing them as graphics.

4. **Big chunks of text are off-putting.**
   Break up text using different fonts, colours and appropriate pictures. Place important bits of text into boxes, or use a bigger and/or bold font. The importance of images and good design cannot be overestimated.

5. **Call attention to facts.**
   Devices such as '*It's Amazing!*' or '*Did you Know?*" or '*Top Five Facts*' can be used to position short, succinct and interesting (or important!) facts where appropriate for the subject matter.

6. **Create opportunities to recap information.**
   This can be accomplished with quizzes, multiple-choice questions, or simple bullet points where the subject matter is inappropriate for the lighter touch. This will give adults the opportunity to check whether the reader has understood what they have read, and it reinforces learning.

### Learning by example

To produce text that is at an appropriate level for a particular age group, it helps to analyse material that's already successful.

**Look at books** in the children's or young adults' section of a bookshop or library to get an idea of the vocabulary and styles that experienced writers use. Non-fiction books are likely to be more helpful than fiction books. 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 simple, not challenging.

**Look at magazines, comics and websites** aimed at the target age group. Many of them have creative, imaginative approaches to providing facts and information. Look for layouts and design devices (such as information boxes, activities, artwork and photographs) that have impact.

If possible, test some draft text out 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.

## 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 loved one, they might be fearful that the person will die, or they may need support through a bereavement.

- It can be helpful to warn the child that the material might be upsetting. This prepares them emotionally.
- It is wise to seek guidance from health professionals who deal with those children and young people that the health information is targeted at. They can suggest a level of detail that is suitable for the age range, or ability level, and provide the medical terms that they would expect to use with the children and young people.
- Try and keep terms, vocabulary and explanations consistent with those that may appear in other information that the child or young person is given. This is especially true for sensitive subjects where the young person may feel uncomfortable seeking clarification, or where euphemisms are commonly used.
- Keeping the information focused on one key area that you want to address means the reader does not have to deal with too much information at once.
- Using 'real-life' stories to explore difficult subjects is an effective technique, especially with children and young people.

Finally, ensure the material gives clear advice on how and where to get support, help, or more information.

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## The case for involvement

Every clinician knows that good care always starts with listening to the patient. The NHS is striving to do this on an organisational level too, and informed choice has become a cornerstone of UK health policy. The guiding principle is that people should be given control over their own health, which means they need high quality information. In addition, the public should have a chance to participate in the planning and improvement of services.

As a society, we increasingly recognise that these ideas should apply to children and young people, as well as adults.

A recent example is the Children and Young People's Health Outcomes Forum, which 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 heightened efforts to involve young patients and their families, and improve care.

You'll find a list of many relevant NHS and government policies in the references at the end of this chapter, and more information sources in **Chapter 5**.

### Involvement in services

For a view from NHS managers and healthcare professionals, see Involving Children and Young People in Health Services, available at www.nhsconfed.org

To hear from patients and service users, see the National Children Bureau's evidence review: Listening to Children's Views on Health Provision. It's available at www.ncb.org.uk

The same philosophy of involvement and consultation is vital when you're producing health information, and there are huge benefits for everyone involved. Bringing children and young people into the process from the start will:

- Ensure your information is relevant, and therefore more likely to be used
- Offer new insights for professionals who are working with young people
- Help young people learn more about their own health
- Build confidence and self-esteem
- Show young people that their opinions, ideas and experiences matter
- Prove that they really can make a difference.

Of course, children and young people in general will benefit from improved information, and from staff and organisations that are more sensitive to their concerns.

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.

The Information Standard

### The Information Standard

**The Information Standard is a certification scheme for organisations producing evidence-based health and care information for the public.**

To meet the requirements, information producers must demonstrate that they understand and meet the needs of their key audiences. They must also use feedback from the target audience to improve their information and development processes.

To find out more, visit the website www.theinformationstandard.org

## 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. So take special care to consider their 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 individuals 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 asylum seekers
- Have a disability or special needs
- Are gay or lesbian.

Of course, it is also vital to include children who share the attributes or experiences of your target audience.

Try to base your audience analysis on facts rather than assumptions. Find population statistics about the condition or health topic you are writing about, and about the geographical area you hope to cover. For example, if you are targeting childhood obesity, seek data such as prevalence and trends according to age, gender, ethnicity and socioeconomic factors such as education or income.

Then when you are engaging with children and young people, make every effort to include a representative group.

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. You could try contacting:

- Schools
- NHS organisations
- Local authorities
- Youth organisations
- Faith groups
- Voluntary groups.

All of these organisations will have many other priorities, so try to fit your work in with these or, better still, show how it helps to meet some of their own objectives. You may have to be persuasive about the benefits of involvement and provide reassurance about the process, because they will also be protective of the children and young people they work with.

It's 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 individuals may not want to be involved, or they may have a change of heart along the way. You'll have to be guided by the child or young person, their parents or carer, and the professionals looking after them.

### 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, the NSPCC is a good starting point.

Visit their website at: www.nspcc.org.uk

## Practical tips

We are all individuals and what works well for one person may not suit another. For example, some children and young people will enjoy group discussions and activities, while others feel more comfortable on their own. Some like reading and writing, but others do not. Digital media is popular with children and young people, but not everyone feels confident with it. Remember that some families do not have access to the technology, and some individuals just don't enjoy using it. Communication, language or learning difficulties can create additional barriers to understanding and expression.

Whatever approach you take, it also has to be appropriate to the age group. Make it 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.

Bearing all of these factors in mind, it makes sense to offer a few alternative ways for children and young people to get involved in your project. Try to make sure there's something for everyone.

If you opt for discussions and activities, smaller groups often work best. This gives everyone 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 in addition to the group session.

It helps to have a facilitator who is not involved in the care of the participants, or in producing the information. The children and young people will feel more at ease, and free to give their honest opinions. Having older children lead the younger ones can also be an effective approach.

For meetings and group activities, attention to the basics makes it a positive experience on the day:

- A safe and comfortable environment is essential
- Make sure everyone understands the importance of confidentiality
- Music and refreshments add enjoyment
- Timing is important - not during school hours, and not too long
- Provide help with making travel arrangements
- Make sure expenses are covered, to avoid exclusion
- Accommodate any special needs or disability.

To help ensure inclusive participation, consider using video links so that individuals who can't travel to the venue can still take part.

Some organisations also run online forums, invite comments by email or carry out online surveys to gather ideas or feedback.

Whatever format you choose, let your participants know how much you value their contributions. Payment can be problematic, for example if the activity was carried out at school. It might also affect benefit payments. However, everyone appreciates a thank you, and a note from the chief executive might be in order. Certificates and small prizes are popular, too.

When it's ready, make sure to share the final result with your group, and explain how their input made a difference.

### Useful resources

The Association for Young People's Health provides a package of resources on involving young people, available at www.ayph.org.uk

**Case Study** | Al Goes to Alnwood: Produced by Northumberland, Tyne and Wear NHS Foundation Trust

Alnwood provides medium secure inpatient assessment and treatment for young people up to 18 years who have complex mental health needs, including those with a learning disability. NHS England commissions Alnwood as part of the secure forensic mental health service for young people. It is one of a small number of centres nationally providing highly specialist multi-disciplinary care for young people requiring treatment under the Mental Health Act 1983.

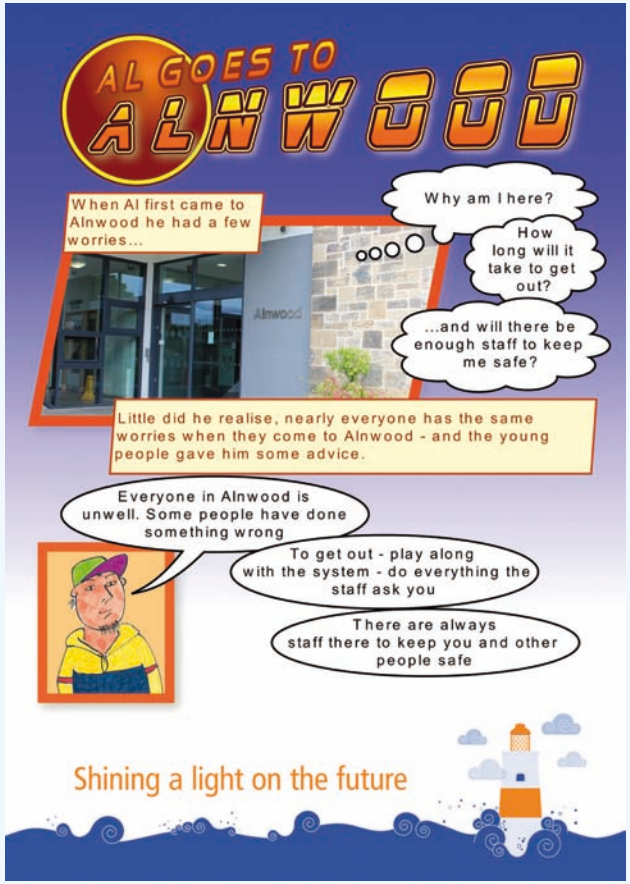
This booklet, which combines a photo-feature and comic book style, aims to reduce anxiety in young people who are to be admitted to Alnwood, by giving them information about the clinic in an accessible format. It does not require high literacy levels or long periods of concentration to take in the information.

Young people in the clinic had previously requested more photos in material about the clinic, and a comic format appeared more child-friendly.

It was produced with contributions from young people resident in the unit, as a summer activity. They had an input into the storyline, shot and edited some of the photos, and helped with the layout and artwork. As a result, the story is told directly from their perspective, reflecting their thoughts, feelings and experiences. This involvement also gave the young people an opportunity to develop their creative and practical skills.

**Tip:** *'Get information across in stories rather than just lists of information, and try to use less words and more pictures wherever possible.'*

You can see the comic at:
www.ntw.nhs.uk/pic



**Case Study** | My Life: Produced by Diabetes UK

Involving children aged five to nine has been at the heart of development work on My Life, a printed magazine and app for IOS, Android and Kindle HD. This will be an update for Tadpole Times, a magazine that has been in production for many years, which was out of kilter with current trends in children's media.

The new magazine and app will be based on a next generation of the My Life characters established on the Diabetes UK children's website, which is also being refreshed.

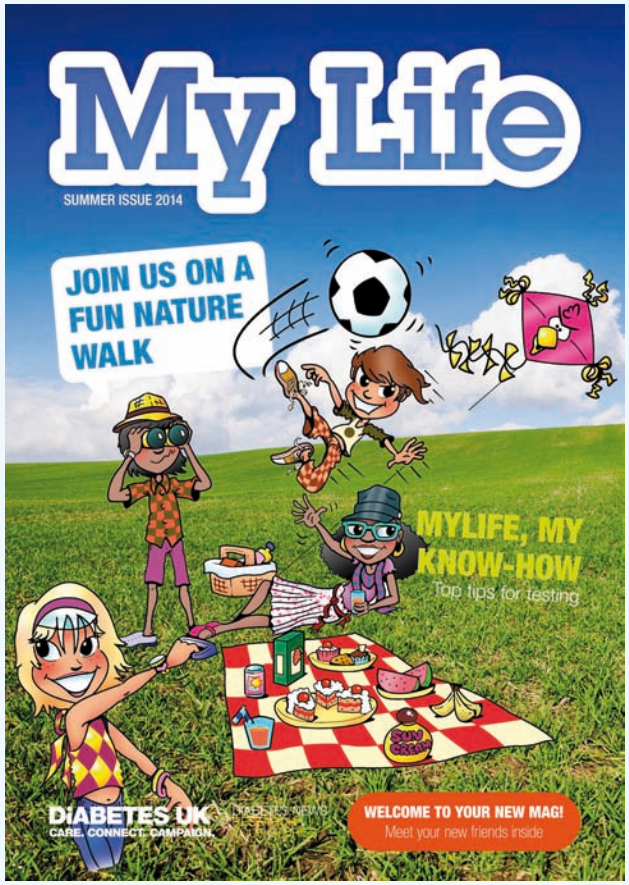
Initial feedback from readers and desk research was followed by informal testing with children in the target age group, and their parents. This informed the creative development of several concepts, which were taken to focus groups and to individuals identified through social media.

Diabetes UK also ran an incentivised survey in the last issue of the 'old' magazine. Children strongly favoured characters that they could personally identify with or could look up to.

A communications agency with experience working with this target audience was commissioned to help with the research and testing the materials, and an evaluation framework has been put in place.

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

www.diabetes.org.uk



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## Holistic approach

Information is just one part of the communication process between health and other care professionals, and children or young people. A resource can rarely do the job on its own and material is often part of:

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

Many of the case studies in this guide provide excellent examples of this holistic approach, including the one here about promoting physical activity.



**Case Study** | Play Your Way to 60 Minutes a Day: Delivered by Newham Council and Resonant Media, supported by the British Heart Foundation

For children aged seven to 11, home and school are the biggest influences, so this social marketing programme to increase physical activity involved children, parents and teachers at every stage. The key to success was discovering the priorities that could motivate each group, and the barriers that had to be removed.

After extensive consultation, it became obvious that recommendations had to be easy to follow, fun for the children, and provide valued benefits such as better behaviour and school performance. People also wanted very local information, about activities that were nearby and available at convenient times.

The team produced a suite of simple and practical tools and interventions. There were teaching resources, including workbooks and a seven-day challenge with stickers to award. Children were given a paper flying disk - printed with tips on staying active - to take home and share with the family.




Parents were important and trusted ambassadors, giving out information at the school gates and on open evenings.

The pilot project was evaluated independently, and the results were impressive. Awareness of official physical activity recommendations increased from 24% of children to 57%, and grew from 45% to 70% among parents. Behaviour changed, too, with eight in ten children saying they were more active as a result of what they had learned.

**Tip:** *'You really have to work with the people who will use and deliver your information. It's crucial to understand what's important, from their perspective.'*

www.resonantmedia.co.uk

## Principles of communication

The General Medical Council provides useful advice on communicating with children and young people, emphasising that it is important to:

- Establish 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 their parents or carers.

Honesty is also crucial. The instinct is to protect children so it's not always easy to decide how much they need to know, and when giving too much information at the wrong time would have negative consequences. The key is to be reassuring, but truthful.



There are various situations in which this communication might take place, and some of these are discussed below. However you are communicating the information, start with what children and young people already know, and do not make assumptions about their knowledge and understanding.

## Patient consultations

The information you are creating might be most appropriately given to the child by a health professional, in the course of a consultation.

If a child has just been diagnosed with a serious or long-term condition, it is usually best practice to arrange another 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 very helpful. Following up important conversations in writing can also be important, as much of what is said in a consultation may not be remembered. This also enables the clinician to reassure the child and engage with them further, if they recognise that the process may be difficult.

Think about ways you can involve these professionals in creating the resource, as their experience will be invaluable. They will also be able to advise you on effective ways to promote and distribute your resource among their peers.

### Pitfalls to avoid

When the National Children's Bureau asked children and young people about their own experiences, they identified these barriers to good communication:

- Staff talking to parents instead of the child or young people
- Use of terms they don't understand
- A lack of respect from professionals (although many staff are kind and respectful)
- Not being involved in decisions
- Care settings that are unwelcoming or not age appropriate.

These difficulties are amplified for vulnerable individuals with communication, speech or language disorders, or those 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, when they are making the transition to adult services.

## Parents and families

Family-centred care is the standard that services aspire to, so it's also 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. On the other hand, you can't assume that all young people will want their families involved from the outset.

For younger children, this might mean producing a resource that their parents can share with them, such as a storybook. You can see an example of this approach in the case study here, about Parkinson's UK. There is another example from Breast Cancer Care, on page **41**. Try to build in opportunities for the child to ask questions and voice their fears. Make sure to give the parents some ideas or tools to check the accuracy of their child's understanding, and to identify any important gaps.



For older age groups, it might be useful to provide parallel information resources for young people and their parents and carers, covering the same ground.

Of course, it's vital that the information provided to everyone in the family is consistent in terms of facts and key messages.

**Case Study** | My Gran has Parkinson's: Produced by 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 to meet the Information Standard (see page **21**), 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 key role in assuring quality.

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

See the storybooks at:

www.parkinsons.org.uk






**Case Study** | Your Life / Their Life: Produced by the National Children's Bureau

This set of leaflets for young people living with HIV is complemented by material for their parents, who may also have HIV themselves.

Approaching and entering adulthood with a long-term, sexually transmissible and highly stigmatised health condition poses a range of complex challenges for young people, as well as for families and professionals. The 'Your Life' leaflets are part of a wider project on transition to adulthood, funded by the Department of Health. Topics include: growing up; work and careers; further and higher education; independent living; rights; and talking to others about HIV.

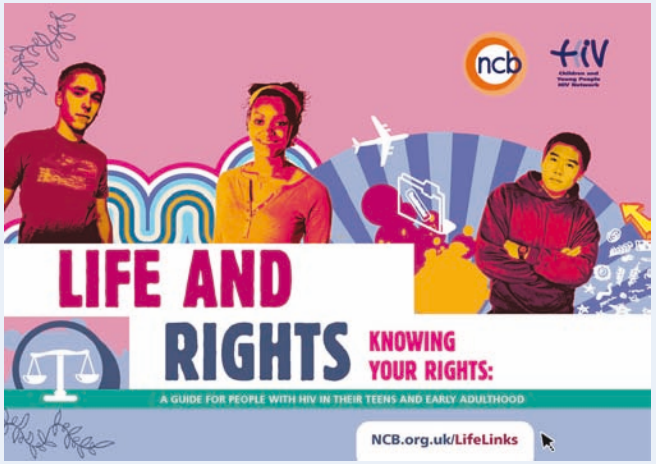
'Their Life' is an accompanying leaflet aimed at helping parents and carers explore some of the issues involved in parenting a young person who has HIV.

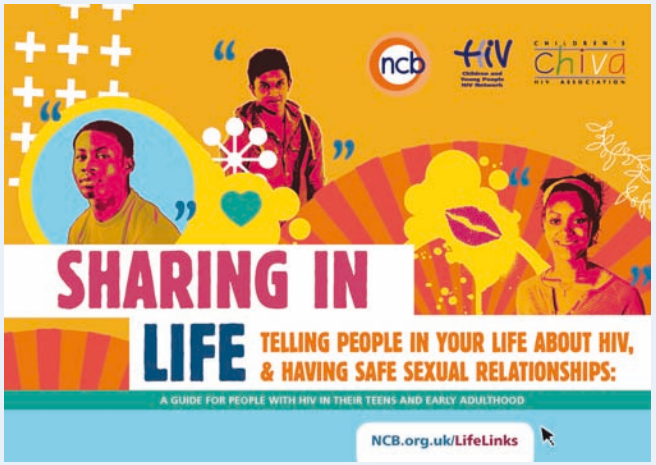
It addresses: feelings parents and carers may have about their children growing up; what young people may need from their caregivers; and how the transition from paediatric to adult HIV health services can impact on young people and their parents.

The team was keen to avoid duplication so they researched existing resources. One of the leaflets, 'Sharing in Life' was produced jointly with the Children's HIV Association, using some of CHIVA's web-based material as a basis from which to develop the content. NCB's Research Centre has formally evaluated the overall transition project, including the leaflets.

**Tip:** *'Get input from the people who you'll be relying on to distribute your resources, and remind them periodically after publication.'*

See the resource at: [www.ncb.org.uk/hiv](http://www.ncb.org.uk/hiv)



## 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. It's not a service to introduce lightly, because you must have policies and procedures in place to handle issues such as safeguarding, data protection and bullying.

Consider what you will do if no one answers a post, leaving the young person feeling even more lonely and isolated. How will you ensure that damaging or inaccurate information is not shared? Is it simply a forum for support, or do you also want to use it as a channel for education? Peer support forums can also pose real ethical challenges, especially in sensitive areas such as mental health.

All of this means you will need an appropriately qualified moderator who can keep an eye on the forum, and respond quickly to any problems.

For a good example of an online health community for young people, visit youthhealthtalk.org.

### Supporting each other

Evaluation is crucial, because the evidence for peer support is mixed and we aren't always sure about what works, and what doesn't.

Teachers are another group of obvious influencers: they have the skills and they know and understand their pupils well. For example, in England, schools are encouraged to make provision for personal, social, health and economic education (PSHE), while in Scotland, health and wellbeing is part of the national curriculum. Therefore, it's not surprising that 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.



**Case Study** | NHS Explorers Primary Resource Pack: Produced by NHS England and AhHa Publications

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.

Children across England have really taken to Monkey, a character featuring in picture books, leaflets, songs, You Tube videos and most of all as a friendly puppet. He has visited every primary and special school in England, as part of a resource pack sent out to support lessons in PHSE. The lessons teach children about NHS 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 an experienced teacher 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 undergone an initial evaluation by academics at Liverpool John Moores University, and this will be followed by a full research report. It was also a runner up in the 2012 Patient Experience Network Awards.

**Tip:** *'Be flexible and never say no. Be really open to lots of different ideas. Set your standards really high and expect that will happen - then it will, because you're determined.'*

Visit Monkey at: **www.monkeywellbeing.com**



## Independent information seeking

For children and young people, the internet, mobile phones and gaming are simply part of their everyday world. According to Ofcom, among children aged five to seven, 82% use the internet. The figure rises to 96% in children aged eight to 11, and it's 99% in the 12 to 15 age group.

### Digital media trends

For a rich source of data on the ways that children and young people access digital media, see Ofcom's 2013 publication, Children and Parents: Media Use and Attitudes Report, available at: **stakeholders.ofcom.org.uk**

So it's 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.

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

In a survey by the National Children's Bureau, about half of teenagers (47%) said they use the internet to find health information.

When asked about the sources they use, young people were able to give multiple responses, and by far the choices most often mentioned were parents (62%) and teachers (55%). About four in ten (43%) mentioned health centres. Friends were not always seen as a reliable source of information, but they were valued for their support.

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



## Apps for health

Ofcom reports that six in ten young people aged 12 to 15 own a smartphone, so mobile apps are a potentially useful new channel for health information. However, this technology is still relatively new so there is little research to tell us what works, or what young people really want.

In one small but in-depth study, university students valued accuracy, security, ease of use and apps that lift their mood. They also liked the ability to track behaviour and progress towards goals. Social media functions were seen as unnecessary and off-putting.



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## Getting started

Before starting on any information project, there are a number of 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

- ✓ How are you going to **fund** development and production?
- ✓ What is the **budget**?
- ✓ How will you identify the information needs of your **audience**?
- ✓ How are you going to **involve** children or young people?
- ✓ How will you ensure **safeguarding**?
- ✓ How will you involve **experts** in communicating with children (for example, teachers, psychologists, play services or children's nurses)?
- ✓ How will you ensure clinical **accuracy** and **relevance**?
- ✓ What **format(s)** should you use?
- ✓ Do you need help from **creative experts** for writing, design, or multi-media?
- ✓ How are you going to **disseminate** the materials effectively?
- ✓ What will you do for **publicity**?
- ✓ How will you **evaluate** the materials, their impact and their use?

## 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 might also want to refer back to page **16** of this guide, where you can read advice from a children's author, with tips on engaging young readers.

In addition, many organisations offer specific services and information for young adults aged 16 to 24. Throughout this guide, you'll find some good examples of work for young people making the transition to adulthood. These include the National Children's Bureau leaflets on HIV (see page **33**) and the Young Parent Survival Guide from NHS Health Scotland, highlighted later in the chapter.

### 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.

Storybooks can also help to explain what is happening or what to expect. The projects profiled on page **32** from Parkinson's UK, and here from Breast Cancer Care, illustrate how this comforting and familiar format can work well for younger children, both in print and digital media.

According to Ofcom, tablets are becoming the 'must have' device, even for the very young. Among children aged three to four, 28% use a tablet computer at home. One in eight children in this age group uses 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 it is best designed for use by parent and child together. This is just as true for traditional media like storybooks.

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 just starting to use books and digital formats to find information. However, the spoken word, role-play and pictures are also 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.

**Case Study** | Mummy's Lump: Produced by Breast Cancer Care

Very high production standards really shine through in this storybook for young children, which is available in print, and as an e-book for iPad, iPod Touch and iPhone. The resource was originally published as a traditional storybook, and the charity decided to add the digital formats, in response to access statistics for its website.

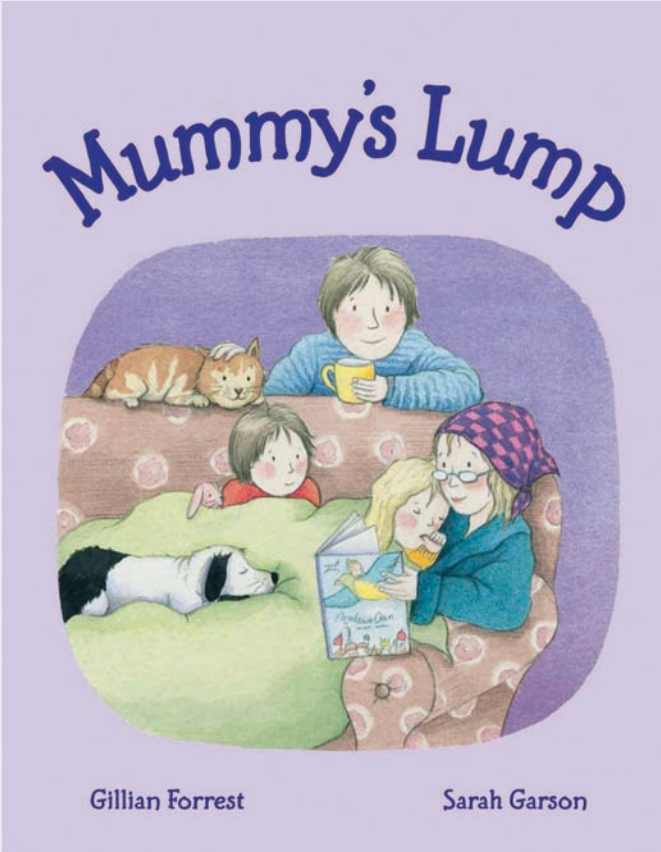
Both the text and illustrations were created by professionals specialising in children's books. A specialist eBook publisher was engaged, and the read-aloud version of the book was narrated by the actor Zöe Wanamaker.

The book is intended for any family needing to talk about the difficult subject of cancer. It covers diagnosis, going into hospital, treatments and hair loss. The resource fills an information gap identified in research by the Breast Cancer Care team, who found that existing material was either very US-based or aimed at older children. It also follows on from academic research at the University of Oxford, which looked at the perceptions of children whose mothers were diagnosed with breast cancer, and what children understand about breast cancer and its treatment.

The content was extensively user-tested by children and parents alike, and their comments guided all aspects of editorial development. The e-book was highly commended in 2013 British Medical Association Patient Information Awards.

**Tip:** '*Be clear about your purpose and your audience. Enjoy your work!*'

See the storybook at: **www.breastcancercare.org.uk** or download it from iTunes **here**.



### Older children

Children aged between eight and 11 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 judgments and decisions.

This age group likes the question and answer format. They also enjoy 'amazing facts' or 'did you know?' features. Again, 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 can't be overstated, whether you are using traditional or digital formats. So you may also want to look at popular games, websites and apps, to see what your audience likes.

In the UK, the average age for starting to use the internet is about eight. However, in a European Union survey, most children aged nine to 10 were still building confidence as internet users. There is a shortage of evidence about the best layout and content for children's websites, and design conventions are still taking shape. One study of 100 factual websites for children, by Jochmann-Mannak et al and listed in the references at the end of this chapter, provides some fascinating examples and is well worth reading.

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.

Don't forget more traditional media entirely, because one in 14 children aged 5 to 15 does not access the internet anywhere. Also some children have Internet access at school, but not at home.

One tried and true method is stickers and reward charts, which worked very well in projects by Asthma UK (see page **14**) and Newham Council (see page **29**).

Remember that families and schools are a good way to reach children of this age, while providing support from trusted adults. For some examples, please see the case studies about Newham Council (page **29**) and NHS England (page **35**). The Children's Cancer and Leukaemia Group (CCLG) has also designed a resource that can be used in schools, to help older children understand what is happening - and how to respond - when one of their peers is diagnosed with cancer (see the **next page**).

**Case Study** | I have a friend who has cancer: Produced by Children's Cancer and Leukaemia Group

When a friend is diagnosed with cancer, young people often worry about what to say and how to give support. Years later, they can still wonder whether they said or did the right thing at the time.

To help children and young people aged 11 years and up, CCLG created this simple poster that folds up into a pocket-sized card. A young person can discreetly give it to friends, or it can be shared as a classroom resource. The design is up-to-date and friendly, with bite-sized chunks of text that don't overwhelm the reader.

It's not intended to be all embracing in terms of information or answers, but instead gives pointers to friends on how they might react, and help their friend with cancer.

Professionals, parents, children in treatment and their friends were consulted during every stage of development, resulting in some significant changes along the way from initial concept to final result.

As with all of CCLG's publications, health professionals play an important part in distributing the resource. It can be downloaded from the charity's website but it is mainly passed on by staff in children's cancer treatment centres, who also visit schools and distribute the poster as appropriate.

**Tip:** *'Have clear objectives from the start about what you want to achieve - time spent in the planning stage pays dividends later on.'*

See the resource at: **www.cclg.org.uk**



### Teenagers

By secondary school, most young people are learning to verify the accuracy and reliability of information, and form and express their own considered opinions. They are starting to detect bias, are capable of understanding quite complicated concepts if they are explained in a clear way, 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 common, too, and three in five young people aged 12 to 15 own one. Of all the media they have access to, this group says they would miss their phone the most.

This age group usually responds well to high quality factual information. Question and answer formats are good for communicating facts and addressing worries, while personal stories are important for making the information relevant.



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

For young people with a long-term condition, the chance to meet peers 'in real life' is also highly valued. Can you run camps, workshops or other events? Finally, do remember that young people can also take a very active role in creating and disseminating health information themselves. They are also great at promotion and publicity.

**Case Study** | Yheart website: Produced by the British Heart Foundation

This award-winning website provides health information for teenagers, including games and interactive learning opportunities. One aim is to increase understanding of the heart and to help young people avoid risk factors of heart disease later in life. It also provides opportunities to get involved in BHF campaigns and volunteering.

A section of the site, meet@ teenheart, is dedicated to supporting teenagers living with a heart condition. This offers advice, medical information and the option to set up and attend events. There is also a linked Facebook page and YouTube channel.

The content and activities are heavily user-led. Young people continually generate ideas through social media channels and in face-to-face workshops.

Their involvement has been invaluable in keeping content relevant to the ever-changing teenage culture.

Cardiac nurses are also vital to the project, ensuring the content is relevant and valuable, and referring young heart patients and their families to the site.

The BHF team also engaged with an educational charity, the University of the First Age, to ensure the website would support the school curriculum, and provide a resource that teachers could use in their lessons.

Partnerships like this, along with search engine optimisation and social networking, extend the reach to young people in every community and with a broad range of interests.

**Tip:** *'Know your audience, check you know, and then ask again!'*




Visit the website at: [www.yheart.net](http://www.yheart.net)

**Case Study** | The Young Parent Survival Guide: Produced by NHS Health Scotland, in partnership with One Parent Families Scotland

Teenage parents need extra support as they navigate new experiences and responsibilities. This guide has key information and clear, reliable advice for expectant teenage parents who wish to continue with their pregnancy, through to early parenthood. It explains what to expect from maternity and primary care, and covers issues such as coping with pregnancy and becoming a new parent, money, benefits and legal rights.

The publication is given to mothers aged 19 and under, at the first maternity appointment with a midwife, in addition to Ready Steady Baby.

Crucially, the guide was developed with input from young mothers and fathers during pregnancy and the postnatal period, and from primary care health professionals. The teenagers in the focus groups fed back on the layout and content of the publication, influencing the look and feel as well as the addition of new areas of information important to young parents. Their involvement ensured appropriateness for the age group.

Working with an in-house editor and designer helped the team respond quickly to advised changes, and the partnership with One Parent Families Scotland assisted with production and evaluation.

**Tip:** *'Remember who the target audience is and work with them to ensure they are listened to in a professional and appreciative manner.'*

See the guide at:
www.healthscotland.com



### Accessibility

It is important to think of all your potential users from the outset. For example, the needs of children and young people with disabilities, including those with hearing loss or impaired vision, must be taken into account.

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 their 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 (2010) makes clear that it is unlawful to discriminate against a disabled person, for example 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, include visual communications, and when using videos, to arrange subtitles and / or British Sign Language (BSL) translation where needed.

#### Accessibility guidance for the NHS

NHS England is developing a framework on producing accessible patient information. NHS organisations will be required to meet these standards and the guidance will be useful for any information producer.

Keep up-to-date at:
**www.england.nhs.uk**

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. Make provision for audiences with:

- **Hearing loss:** Include visual communications, and when using videos, arrange subtitles and/or British Sign Language (BSL) translation. There are guidelines from the National Deaf Children's Society, Action on Hearing Loss and the Web Accessibility Initiative.
- **Visual impairment:** Remember to budget for accessible options such as large print, audio or Braille. Guidelines are available from Action for Blind People and the Web Accessibility Initiative.
- **Speech, language and communication needs:** The children's communication charity, iCan, offers a wealth of information and advice at: **www.ican.org.uk**. So does the disability charity, Scope: **www.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 **www.easyhealth.org.uk**. There are also guidelines from Mencap.

Thanks to Vicki Kirwin, Audiology Specialist, National Deaf Children's Society, for comments on accessibility for children and young people with disabilities.

### Say it with symbols

Using symbols can make your material more accessible to people who find it difficult to read text.

Visit Widgit at: www.widgit.com

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

### Languages other than English

A growing proportion of children in Britain have a first language other than English. In 2013, according to the Department for Education this applied to nearly 14% of children in secondary schools and about 18% in primary schools. Therefore, it's increasingly important to ensure your information is accessible to this group.

Using clear, plain language is helpful when your audience does not have English as a first language. It also aids those with communication needs, and improves understanding for all who use your material.

If you are thinking about producing a translation, include young people from these communities early on, at the planning and consultation stage, rather than seeing this as a simple add-on at the end of the process.

### Cultural diversity

It's common to worry about 'getting it right' when it comes to cultural diversity, but there is no right or wrong answer, because people do not fit into homogenous groups - every individual is different. What matters is intent, along with an effort to understand and a mindful approach.

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

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



Then ask yourself what angles other people might take, and how this could be addressed in the work. It's important to think broadly and do your best to ensure the information can reach a wide range of children and young people who might need it.

And if you don't know what your audience wants, don't be afraid to go out and ask them. The end result may not be perfect, but people will still understand and appreciate that you are trying to do a good job.

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.

### Information for young carers

In England, there are some 166,000 young carers looking after parents or family members with disabilities, physical or mental illness, or substance abuse problems. A report from the Children's Society says this figure has grown from 139,000 in 2001 and probably under-represents the full number, because so many young carers go unrecognised by professionals.

When someone in the family has a health condition, these 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 also 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 professionals on the ground. This is why the Children's Society has been training health professionals such as school nurses and GPs, to help them spot young carers and give them the support they need. They also work with professionals in schools, mental health trusts, social services, the legal system and services for refugees and asylum seekers. Ultimately, the aim is to free children and young people from inappropriate caring responsibilities and give them a chance to grow and achieve.

Young carers need information that's tailored to their age and level of understanding.

There's no one size that fits all. It's about asking 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 also consults intensively with young carers, involves them in delivering the work, and offers them a secure social network and other resources on their own website at: **www.makewav.es/ycif**.

Thanks to Jenny Frank, Programme Manager at the Children's Society, for her substantial contribution to this section on young carers.

## 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, to ensure accessibility, if your audience is segmented into different groups, or if you want to accommodate a wider range of learning styles. The tables on the following pages look at some of the options, and summarises their pros and cons.

## Websites and apps



### Strengths

- A website is now a must-have for every organisation, so you can build on existing infrastructure.
- Text, audio and visual can all be provided, increasing accessibility and accommodating different learning styles.
- Websites offer many opportunities for children and young people to contribute, ask questions and stay involved.
- Apps, especially, allow for personalisation and interactivity.
- The majority of young people over the age of 12 have a smartphone and many younger children are allowed to use their parent's smartphone with supervision.

### Limitations

- Children and young people may find it hard to locate your website, or not consider looking for it. You will have to invest in carefully developed search engine optimisation (SEO).
- While internet use is widespread, not all individuals have access, especially in lower income households.
- You will need a website version that also works on smartphones.
- Apps are often a 'walled garden' - that is, the material users can access is limited by the device they have (a specific tablet, smartphone or e-book reader).
- Text that works in print will not necessarily work online, because we read differently on a screen. You will probably need to adapt any existing or companion print materials.
- Can be an expensive option.

## Picture book or storybook



**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 for a high standard.
- Can be expensive to produce.
- Should only cover small amounts of information.

## Leaflets



**Strengths**

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

**Limitations**

- Limited information that can't be interrogated.
- Might be boring for young people.
- Consider accessibility for those with low literacy, a first language other than English, those with visual impairment.

## Audio



**Strengths**

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

**Limitations**

- Some individuals will not have access to the technology needed.
- No scope for illustrations.
- You will need to produce an alternative for those with hearing loss.

## Videos and films

### 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 those who do not have English as a first language.
- Animations can clearly explain medical 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 those with visual impairment or hearing loss.
- Some individuals will 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 those with low literacy levels or whose first language is not English.
- Can address social or emotional issues through storytelling.

### Limitations

- Some individuals might find the format off-putting.
- Inaccessible for those with a visual impairment.
- Getting the artwork and tone just right can be a challenge.
- Can be an expensive option.

## Social networking and online communities

### Strengths

- Very accessible and familiar format for most young people.
- 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

- Requires a moderator, and strict controls to ensure safeguarding, confidentiality and compliance with data protection laws.
- You also need a high level of participation - with enough people posting and responding to comments - for an online community to 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, and they also offer advice, tools and case studies that might be helpful in planning your campaign.

Visit: www.thensmc.com



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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. It's also worth consulting and involving professionals, and looking 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.
  www.gov.uk
- **National Service Framework: Children, young people and maternity services (England)**
  Including updates and related policies.
  www.gov.uk
- **Department of Health, Social Services and Public Safety (Northern Ireland)**
  For latest policy and guidance.
  www.dhsspsni.gov.uk
- **Health in Wales**
  Gateway to health policy, guidance and more. www.wales.nhs.uk
- **NHS Choices**
  Check that your advice aligns with NHS information for the public.
  www.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.
  www.evidence.nhs.uk
- **Scotland's Health on the Web**
  Gateway to health policy, guidance and more. www.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. www.cebm.net

## Education and learning

- **BBC Schools**
  Get in touch with education and find a wealth of high quality resources.
  www.bbc.co.uk/schools
- **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. www.gov.uk/dfe
- **Department of Education Northern Ireland**
  Education policy, reports, guidance and the curriculum. www.deni.gov.uk
- **Education Resources Information Center**
  A gateway to extensive academic research on childhood education worldwide, including health. www.eric.ed.gov
- **Education Scotland**
  Education policy, reports, guidance and the curriculum.
  www.educationscotland.gov.uk
- **Learning Wales**
  Education policy, reports, guidance and the curriculum. learning.wales.gov.uk

- **Office of the Children's Commissioner (England)**
  www.childrenscommissioner.gov.uk
- **Children's Commissioner for Wales**
  www.childcom.org.uk
- **Scotland's Commissioner for Children and Young People** www.sccyp.org.uk
- **Northern Ireland Commissioner for Children and Young People**
  www.niccy.org

## Involving children and young people

- **Council for Disabled Children**
  Many resources and ideas, plus an extensive programme of involvement.
  www.councilfordisabledchildren.org.uk
- **Expert Patients Programme**
  The Staying Positive peer-facilitated workshops are for young people aged 12 to 18, who are living with a long-term condition.
  www.expertpatients.co.uk
- **National Children's Bureau**
  Useful resources including the Listening as a way of life series. www.ncb.org.uk
- **National Youth Agency**
  Hear by Right helps organisations follow best practice on participation of children and young people. www.nya.org.uk
- **NSPCC**
  A good starting point for information on safeguarding (child protection).
  www.nspcc.org.uk
- **Participation Works Partnership**
  Find training, resources and latest news.
  www.participationworks.org.uk
- **Royal College of Paediatrics and Child Health**
  Resources and guidance on child health, safeguarding, and involvement.
  www.rcpch.ac.uk

## Communicating health information

- **Action on Hearing Loss**
  Accessibility guidelines.
  www.actiononhearingloss.org.uk
- **Equality and Diversity Forum**
  Information, resources, training and guidance to ensure your approach is inclusive. www.edf.org.uk
- **Equality and Human Rights Commission** Learn about your organisation's legal obligations to make health information accessible to all.
  www.equalityhumanrights.com
- **Preschool Learning Alliance**
  Gain insights into early years education.
  www.pre-school.org.uk
- **Fred Rogers Workshop**
  Based in the US, this centre provides a wealth of information and resources on best practice in digital and multi-media education for children.
  www.fredrogerscenter.org
- **Joan Ganz Cooney Centre and the Sesame Street Workshop**
  (US) A great source of information and research on digital media and early childhood education. www.joanganzcooneycenter.org
- **RNIB**
  Accessibility guidelines. www.rnib.org.uk
- **Social Care Institute for Excellence**
  Find reliable guidance on communicating with various groups, including children and young people. www.scie.org.uk

## Creating health information

- **Chartered Society of Designers**
  Find a designer for your project, and learn more about the world of design.
  www.csd.org.uk
- **Chartered Institute of Linguists (translation)**
  Find a translator for your material.
  www.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.
  www.computerweekly.com
- **Edugames Hub**
  Learn more about gaming in education and find a games designer.
  www.edugameshub.com
- **Guild of Health Writers**
  Find a specialist writer or editor. Send an email to the administrator if you are looking for a freelancer. www.healthwriters.com
- **Information Standard**
  Quality mark for health information in the UK. www.theinformationstandard.org
- **Institute of Medical Illustrators**
  Lists specialists in clinical photography, medical art, illustration, graphic design and video production. www.imi.org.uk
- **Institute of Translation and Interpreting**
  Find a translator for your material.
  www.iti.org.uk
- **Medical Artists' Association of Great Britain**
  Find an illustrator for your project.
  www.maa.org.uk
- **Medical Journalists Association**
  Send an email to the Secretary if you are looking for a medical writer.
  www.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. www.societyofauthors.org
- **UK Web Design Association**
  Find a web designer for your project.
  www.ukwda.org

## Further inspiring examples

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

**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.ndcsbuzz.org.uk

**Teenage Cancer Trust**
www.teenagecancertrust.org

**Teenage Health Freak**
www.teenagehealthfreak.org

**Young Minds**
www.youngminds.org.uk

# 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, www.pifonline.org.uk, and complete the feedback form there, or contact the PiF administrator at: admin@pifonline.org.uk with your comments.

If you are not a member of the Patient Information Forum, and would like to find out more about us, please go to: www.pifonline.org.uk or contact the PiF administrator at: admin@pifonline.org.uk