Patient
Information
Forum

Guide to Producing Health Information for Children and Young People

2023 Edition

2023 update funded by NHS England

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.

Copy editing 2023 version: Julia Bell, Freelance editor and patient information specialist. Original 2010 author: Nikki Joule. Design: Arabella Serrels. Images: Unsplash and iStock. Cover illustration: Beano for the RCoA. © Patient Information Forum 2023

Published July 2023 Review date: July 2026

Expert panel

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Thanks to **Dr Sveta Alladi**, the Named Doctor for Looked After Children in the London borough of Newham and **Rosie Vare**, Clinical Information Lead, Teenage Cancer Trust for their support with the 2023 update.

Thanks to **Michael Carver**, Lead Nurse for Violence Reduction, Barts Health NHS Trust, **Wendy Nicholson**, Deputy Chief Nurse Children, Young People and Families, Public Health England, **Emma Selby**, clinical nurse consultant in mental health; Director of Digital Mentality, **Tom Bishop**, Senior Patient Services and Information Manager, Anthony Nolan for their contribution to the 2020 update of the guide.

Thanks to **Vicki Kirwin**, Audiology Specialist, National Deaf Children's Society, **Professor Nisha Dogra**, child and adolescent psychiatry expert at the Greenwood Institute of Child Health, University of Leicester, **Jenny Frank**, Programme Manager at the Children's Society and children's author **Camilla de la Bedoyere** for contributing to the earlier versions of this guide.

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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. It helps put people in control, resulting in better outcomes.

Children and young people are keen to broaden their knowledge. The 2023 Health Literacy Report from the NHS Youth Forum confirms this.

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.

We must account for cultural diversity in all our information. This includes gender, sexual orientation, race, beliefs, social class, age and even politics.

Crucially, we must keep focus on children and young people who are most vulnerable. Examples include children and young people:

- With a higher risk of other illnesses because of ongoing physical or mental health conditions
- With a statutory entitlement to care and support because of a learning disability or special educational need
- At higher risk of poor health because of socio-economic factors
- Who may be in care or care-experienced.

Socioeconomic factors such as poor housing, family low income, family composition, belonging to a black or minority ethnic group can lead to low educational attainment, poor nutrition and lack of exercise.

Introduction continued on the next page

Without intervention, disadvantage persists, resulting in poor health and low levels of wellbeing. Such problems have the potential to be life-long.

Health information is an intervention that can help to tackle and reduce health inequalities. It should be seen as part of a prescription for change.

Not making health information more accessible to children and young people fails them on a grand scale.

And while digital engagement grows in popularity and accessibility, not all UK youngsters have access to the internet. Different formats are still needed.

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, be inspired by some great work.

Accessible, developmentally appropriate, culturally sensitive healthcare information has huge potential to improve child health outcomes, showing information truly is a prescription for change.

Kath Evans, Director of Children's Nursing, Barts Health NHS Trust

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Executive Summary

This guide covers topics related to producing high-quality health information for children and young people.

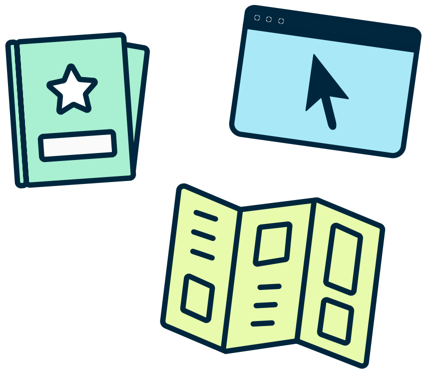
The summary below is a list of the key points covered in each chapter. There are references and further reading at the end of chapters. Also links in the text to more resources and information.

1. Need – why the right information matters

- 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.
- They need accessible information to help them understand their health and wellbeing on their own terms.
- Diversity and the particular needs of your audience must be taken into consideration. Consider language, culture, social needs, disability, sexual orientation, gender and literacy, as well as age and information preference.
- Fresh approaches can help get to people who often miss out on standard health information. For instance, social prescribing.
- Changes and opportunities in the wider world may have a big impact on the health information needs of children and young people. This includes learning from health-related incidents.

2. Health inequalities

- Unaddressed health inequalities can lead to lifelong disadvantage.
- Accessible health information can be part of a prescription for change, helping to reduce health inequalities.
- Using accessibility techniques will help ensure your resources reach a wide range of children and young people.
- There are many ways to improve accessibility. They can often be used alongside each other.
- Plan ahead to help get your resources to groups with known health inequalities. These groups need specific attention to make sure they are reached.
- There are legal as well as ethical reasons for ensuring people with disabilities can use your resources.
- A growing proportion of children in the UK do not have English as a first language.
- Failing to account for cultural and context sensitivities can be a barrier to accessible health information.



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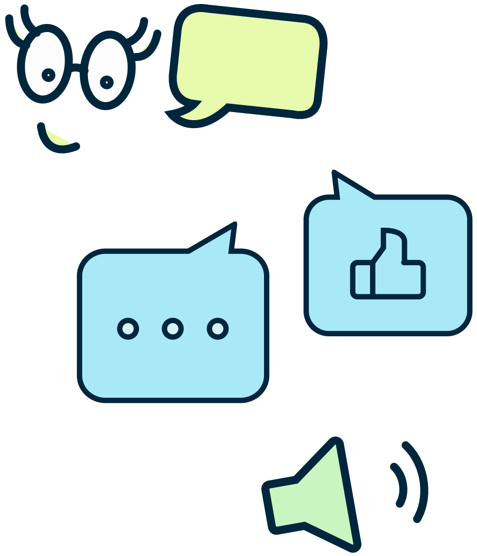
3. Involving children and young people

- Consulting with stakeholders and your target audience from development through to evaluation will make your information relevant and well targeted.
- Greater involvement makes your resources more credible.
- Involving children and young people can aid dissemination and use of resources. Peer advocates can be incredibly powerful in sharing information.
- Health information is about service developments that enhance communication as well as information resources.
- Done well, consultation experience benefits children and young people because they gain confidence, feel valued and learn their opinions matter.
- Research and scoping work are essential to understand your audience and ensure involvement is representative and inclusive.
- Take care to involve children and young people representing groups who might need greater focus to identify and engage.
- A clear safeguarding policy is compulsory.
- Remember to thank children and young people with a letter, prize or certificate, share the end results and share what you changed as a result of their involvement.

4. Communicating health information

- There are core principles of communicating health information that must be followed.
- Scope out existing materials popular with children and young people.
- Appropriateness to age and information preference is important.
- Involve parents, carers and family members significant to the child or young person.
- Other young people can be effective communicators of health information.
- Teachers can be helpful to disseminate trusted information.
- Children and young people are heavy users of social media, but they may not have the skills to assess the credibility 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.
- Always include clear signposting to more information, advice and support.



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5. Content and design

- Draw up a plan at the outset
- The plan must be based on your identified need and target audience.
- Think early about how to achieve regular review, dissemination to a wide range of people in your target audience and evaluation.
- Choose your format carefully. Use assessment of benefits and limitations of each format and ask users what they want.
- Whichever formats you choose, the golden rules of writing for children and young people apply. So do the core principles of health and digital literacy.

6. Evidence and misinformation

- Ensure clinical accuracy and relevance through research and by involving healthcare professionals and other experts.
- Explain any uncertainties where research findings are not clear.
- Be aware of misinformation and disinformation about your topic.

  Knowing what is out there, and where, can help you to combat it with trustworthy information.
- New research, resources and courses about tackling misinformation and disinformation are becoming available.

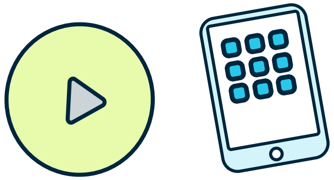
7. Quality improvement through dissemination, feedback and impact

- Think early about how you are going to reach your target audience. Remember to consider how to widen access to disadvantaged groups.
- Include queries about reaching your target audience in your impact and evaluation plans.

- Have a clear picture of the difference you want to make.
- Make sure your objectives are possible to measure.
- Make it easy for users to give you meaningful feedback. Let them know what you are going to do with their comments.
- Consider using different feedback mechanisms for children and young people than for parents and carers.
- Have systems and training in place to ensure feedback and impact information are used to improve your resources.
- There are lots of ways to measure impact. Choose the evaluation methods that match your needs, budget and other resources.
- Impact evaluation may show you are not meeting your objectives in the way you hoped. You can use this information to change your approach to be more effective.

8. Where to learn more – contacts and resources

- This section signposts to resources for exploring topics from the guide in more detail.



Chapter one: 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 health and wellbeing, and to be listened to.
- They need accessible information to help them understand their own health and wellbeing on their own terms.
- Diversity and the particular needs of your audience must be taken into consideration. Consider language, culture, social needs, disability, sexual orientation, gender and literacy, as well as age and information preference.
- Fresh approaches can help get to people who often miss out on standard health information. For instance, social prescribing.
- Changes and opportunities in the wider world may have a big impact on the health information needs of children and young people. This includes learning from health-related incidents.

The right to understand

Children and young people **have the right** to clear accessible information, and to speak up and be listened to about things that affect them.

This includes their own **health and wellbeing**.

To do this, they need information right for their age, culture, context and level of understanding.

They need information that enables them to take part in decisions about their treatment and care.

The National Institute for Health and Care Excellence (NICE) published **guidelines** in August 2021 on maintaining and improving healthcare standards for babies, children and young people.

The guidelines include recommendations for providing high-quality communication and information.

Getting familiar with these ideas can be a useful part of your planning process when producing information resources for children and young people.

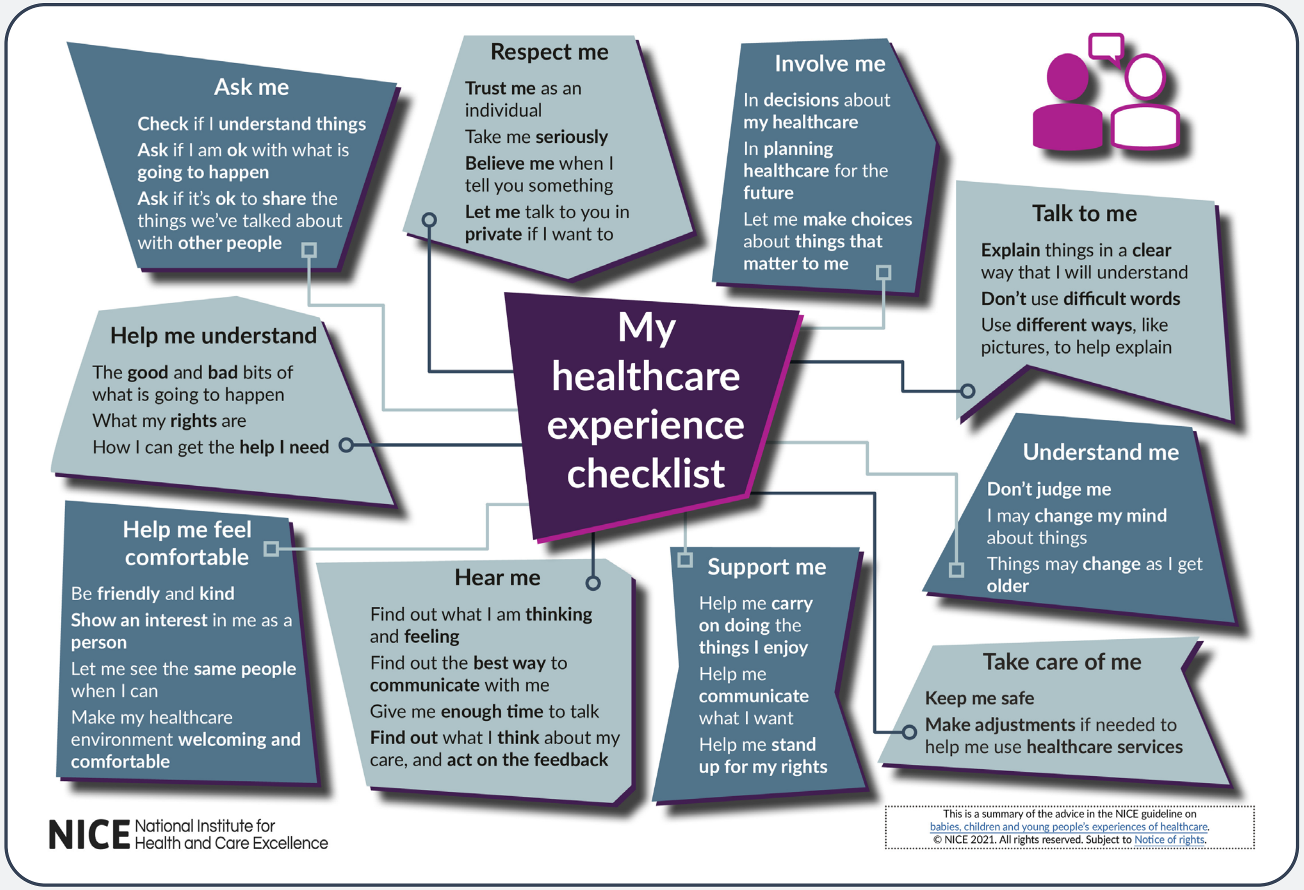
Talk to me

"Adults often see children and young people as passive recipients of healthcare.

This can lead to children and young people not being listened to, having a lack of understanding of their own condition and may lead to problems that can affect future care…

However, having a positive experience can make a child or young person feel confident, empowered and supported to manage decisions about their own health and healthcare…."

Introduction from the young people involved in producing the NICE guideline Babies, Children and Young People's Experience of Healthcare.



My healthcare experience checklist

Ask me
Check if I **understand things**
Ask if I am **ok** with what is **going to happen**
Ask if it's **ok** to **share** the things we've talked about with **other people**

Respect me
Trust me as an individual
Take me **seriously**
Believe me when I tell you something
Let me talk to you in **private** if I want to

Involve me
In **decisions** about **my healthcare**
In **planning healthcare** for the **future**
Let me **make choices** about **things that matter to me**

Talk to me
Explain things in a **clear** way that I will understand
Don't use **difficult words**
Use **different ways**, like pictures, to help explain

Help me understand
The **good** and **bad** bits of what is going to happen
What my **rights** are
How I can get the **help I need**

Understand me
Don't judge me
I may **change my mind** about things
Things may **change** as I get **older**

Help me feel comfortable
Be **friendly** and **kind**
Show an interest in me as a **person**
Let me see the **same people** when I can
Make my healthcare environment **welcoming and comfortable**

Hear me
Find out what I am **thinking** and **feeling**
Find out the **best way** to **communicate** with me
Give me **enough time** to talk
Find out what I **think** about my care, and **act on the feedback**

Support me
Help me **carry on doing the things I enjoy**
Help me **communicate** what I want
Help me **stand up for my rights**

Take care of me
Keep me safe
Make adjustments if needed to help me use **healthcare services**

NICE National Institute for Health and Care Excellence

This is a summary of the advice in the NICE guideline on babies, children and young people's experiences of healthcare.
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A visual summary of the NICE guideline Babies, Children and Young People's Experience of Healthcare

Making choices and decisions

Clear information is vital so young people can give **consent** for examinations, tests and treatment.

Autonomy for young people increases with age and with their individual capacity to understand the decision and its consequences.

Younger children need help to understand what is going on. With clear information, many younger children will be informed enough to make decisions on treatment not linked to urgent care.

Children and young people's questions about their health and healthcare must be answered truthfully and clearly.

Children can understand difficult concepts and distressing information if it is honest and accessible.

Different age groups have different needs

Information needs change as children get older and time passes since their first diagnosis.

This is the case both for treatments and for people living with a long-term condition.

A 4-year-old and a 10-year-old will want to know different things about an X-ray, for instance.

What worked for a child with asthma at the age of 6 may not be suitable when they are 13 years old.

An individual's ability to process information depends on the context. It is harder to understand information at times of stress.

When giving information face to face, allow time and opportunity for questions and be honest about knowledge gaps.

Rarely do we ask children to 'teach back' what they have been told. Using 'teach-back' clearly shows gaps in understanding and identifies misunderstanding.

Intellectual ability to understand a condition is not the same thing as emotional readiness to cope with its impact. Page 51 discusses writing about sensitive or frightening subjects.

A consultation for England's Chief Medical Officer highlights the need for accessible and reliable information to help children and young people find services and support their decision-making.

Too often such information is not there, children and young people cannot find it, or it is not clear whether sources are reliable, especially digital sources.

Parents can also be reluctant to share information with children. Early results from a study underway at the time of writing suggest 40% or parents do not want to tell their child they are coming to a clinic for a blood test. As a result the child cannot access the child-friendly information available.

Ask questions to ensure you are meeting a genuine need

- Have you identified a genuine need among a particular target audience of children and young people?
- How do you know about this need?
- Does anyone else already produce information in this area?
- Are you sure you will be complementing or adding to this information, not duplicating it?
- Who else knows about this need?
- Can you collaborate with them?

Keeping in touch with change that creates new needs | Case study | Mind

When the COVID-19 pandemic struck, mental health charity Mind realised a crisis in young people's mental health was growing fast.

Mind's survey, found young people were more likely than adults to experience poor mental health during the pandemic.

Young people were also more likely to use negative coping strategies such as self-harm.

In response, Mind set out to produce information on self-harm for young people.

The need for this information was urgent. However, the team took the time to co-produce the resources with young people.

As self-harm is a complex, emotive and potentially triggering topic, Mind was aware a particularly sensitive and bespoke approach was needed. The young people needed choices about how they could get involved.

They used a comprehensive and multi-layered engagement plan (see page 57) in order to:

- involve as many young people as possible
- work with young people in a way that felt most comfortable and safe to them
- be clear on what support young people needed to take part.

Led by the young people, Mind produced two resources for the 11-18 age group. The first is for young people who are self-harming. The second is for young people supporting a friend or partner who is self-harming.

Both were initially web-based, but are now also in print. They were launched in June 2021, with Welsh language versions ready from November 2021.

The current satisfaction rate from the feedback form at the bottom of the web pages is 98%, with many positive comments, including the following:

"I like how your [sic] dealing with younger people as there really isn't enough information out there for them like adults."

Visit **www.mind.org.uk**

Policy background

The right and need 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.

Core20PLUS5 – An Approach to Reducing Health Inequalities for Children and Young People is an action plan highlighting groups at particular need of information and support.

Core20 refers to the most deprived 20% of the national population (see below). Many children will face multiple needs.

- Ethnic minority communities
- People with a learning disability
- Autistic people
- People with multi-morbidities
- Young carers
- Looked after children and care experienced people
- Those in contact with the justice system
- People who are homeless
- People with drug and alcohol dependence
- Vulnerable migrants
- Children and young people from Gypsy, Roma and Traveller communities and other socially excluded groups.

The PLUS5 represents important areas of clinical focus: diabetes, asthma, epilepsy, oral health and mental health.

Core20PLUS5 and other recent NHS policies spring from the promises of the 2019 **NHS Long Term Plan**. This puts focus on the health information needs of children and young people.

The plan promises that by 2028, children and young people in England, their parents and carers, will experience a 'seamless service'. This will be delivered by an integrated health and care system designed to reduce health inequalities.

However, the plan is long overdue for a refreshed version promised by the Government since early 2022.

The current review by NHS England **will reportedly learn from the experience of the pandemic, change some goals and add others**.

Understanding the policy background can help create partnerships and support funding applications.

The **Health and Care Act 2022** has the potential to open more doors locally through integrated care systems (ICSs). These bodies have been set up to encourage collaborative work across a geographical area to improve all patient services.

Meeting the increasing need for help with self-care | Case study | Expert Self Care

GP Knut Schroeder, founder of Expert Self Care, knew young people with eating problems find it hard to talk to anyone. They may not know how to seek help.

He had an existing collaboration with the **Bristol Health Partners Eating Disorder Health Integration Team (EDHIT)** and set about creating **The Eating Disorder Support app**. The app offers trusted information about eating disorders.

The team used co-creation to ensure the app met the needs of the primary target audience of older teenagers. An EDHIT user panel of experts by experience were involved throughout.

Quality safeguards were applied. These included **NHS Digital Technology Assessment Criteria** (DTAC), the **Organisation for the Review of Health and Care Apps** and the **PIF TICK**.

The UK-focused app is free to everyone, with no sign-up required – an important point stressed by users.

In addition, local healthcare providers can subscribe and set up their own home page and service directory on the app. They can then refer people to local information.

The app was launched in 2022. Comments received through the integrated feedback button include:

"I wanted to let you know the Eating Disorder Support app is so amazing… It has a wealth of information… that covers so many recovery tools, wellbeing tools, ideas for practical things to make and have to ride the wave, and also help for carers and relatives… it is a one-stop-shop for so much information and support."

Visit **www.expertselfcare.com**

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

Today's landscape

Systematic research into the quality of the wide range of health information available to children and young people is sparse.

A **study by the NHS National Institute for Health Research** found the field is unregulated, quality is variable, resources are not accessible to all, and there are big gaps.

The **Care Quality Commission's review of children and young people's mental health services** identified serious information gaps, including children feeling ignored.

The **National Centre for Social Research ongoing survey of the mental health of children and young people** notes an increased need for reliable health information for children and young people. Factors include COVID-19, an increase in refugees and asylum seekers and the cost of living crisis.

More families are being pushed into poverty, increasing the risk to children and young people of current and future ill health.

COVID-19

An international study looking at children's health literacy during the COVID-19 pandemic found most children said their parents were their main source of information. However, their parents often played down the reality of the illness, especially about deaths, and limited children's access to information.

Children were nevertheless aware that COVID-19 could spread quickly and kill.

This research argues for increased recognition at community and national level of the need to work with children and young people to develop responsive, targeted health information, especially during a pandemic.

Self-care to support mental health

In the financially stretched environment following the pandemic, the focus is increasingly on self-care, particularly for mental health challenges.

GP Knut Schroeder reports, "Eating disorders were made worse by the pandemic, when people couldn't access face-to-face support."

This view is endorsed by the Department for Education's State of the Nation 2021: Children and Young People's Wellbeing report.

"Now, there are not enough mental health service providers to deal with the need. This has led to a push within the NHS and charities to develop digital products to support people." said Dr Knut.

"These cannot replace clinical care, but it can make a difference to know one website or app might help calm and support you."

Cost of living crisis

Children are going hungry, lacking healthy food and warmth, and being sleep-deprived as a result of soaring costs.

Before energy, housing and food costs started to rise, 1 in 3 children in the UK were already living in poverty. Not being able to afford basics takes a huge emotional toll on children and young people and their families.

Good-quality health information cannot stop the financial pressure, but can be vitally important as a source of support, signposting and practical advice.

Health literacy

Health and digital literacy issues affect the whole UK population, meaning **43% of the UK working age population cannot understand and use standard health information effectively**.

There is limited literature on how many children and young people are affected by health and digital literacy barriers.

Children and young people with little or no family support may be especially affected. They can be at risk of having very limited health literacy and likely to have particular communication and health information needs.

This can include children in care, young care experienced people and refugees and asylum seekers. The last group may not have English as a first language. They may be wary of anyone in an official capacity in case anything they say impacts their immigration status.

Digital exclusion also affects people living with social deprivation. For instance, care experienced young people and young refugees and asylum seekers often lack Wi-Fi or resources to buy enough data to run health apps. See page 32.

Action to ease the hidden problem of sleep deprivation

Dr Sveta Alladi, the Named Doctor for Looked After Children in the London borough of Newham, highlights health information needs in young refugees and asylum seekers.

"Sleep hygiene is a big issue because that's how their trauma manifests," she says.

Many of these children and young people lack a sleep routine and or knowledge about sleep hygiene, for example they may drink caffeinated energy drinks later in the day.

In addition, lack of a proper bed or bedding leads to sleep problems for many children living with social deprivation.

A teacher in Leeds has provided beds to nearly 1,400 children in the city and says referrals are continuing to rise.

Looked after children and care-experienced young people

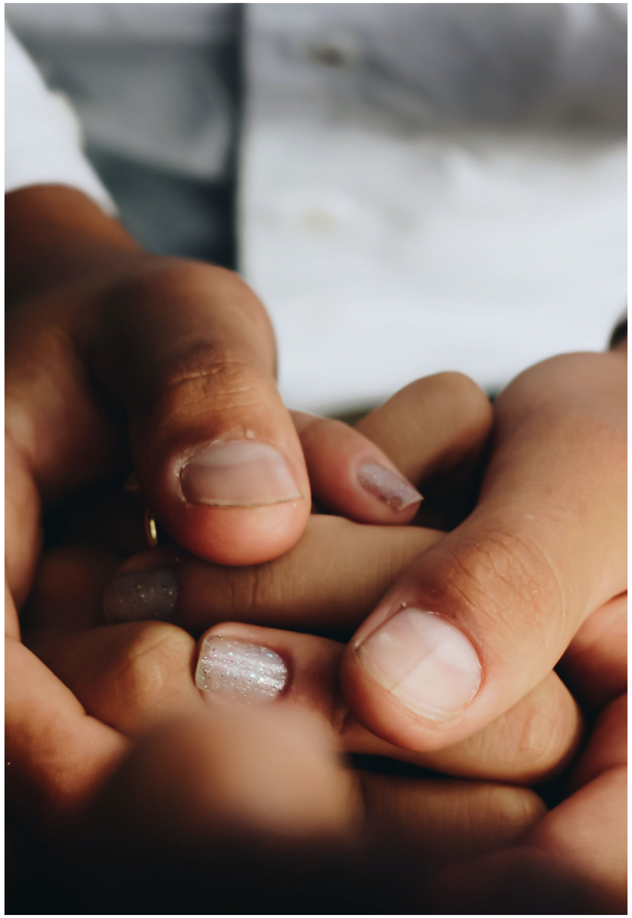
Poor mental health is an acute problem for looked after children and young care experienced people.

This group is around **four times more likely to have a mental health problem by the time they are 30 than children living in their birth families**.

This includes youngsters living in foster care, residential care, hostels or independently, or with their parents or relatives while under the supervision of social workers.

Their health information needs are high, especially as young people in care often feel they're not listened to. They also frequently have problems trusting anyone in authority.

Importantly, it has been shown organisations **involving care experienced young people in the design of services and resources are in a better position to understand how to improve them**.



The vital importance of listening to user experience to drive forward change

Case study | iSupport

International collaboration iSupport was initiated by Katie Dixon, a young person with lived experience of the health system. She raised the question with experts of whether the healthcare world could 'do better' for children and young people having tests and treatments in hospital.

She had undergone health-related procedures since the age of 18 months that left her traumatised into adulthood.

Her experiences continue to affect her ability to tolerate ongoing treatment for her lifelong chronic condition.

Her challenge ultimately led to a collaboration of health professionals, academics, young people, parents, child rights specialists, psychologists and youth workers developing **rights-based standards for children having tests, treatments, examinations and interventions**.

The standards and supporting resources aim to improve the care children and young people receive when they have clinical tests, treatments or examinations. This is by reducing harm and establishing trust.

They were launched across the world in November 2022.
Downloadable resources include:

- Versions for both health professionals and families
- A prep sheet to help children get ready for having a test, treatment, examination or intervention
- Case studies to show how the standards are used in practice.

They are based on the internationally agreed **United Nations Convention on the Rights of the Child**. They are for children and young people aged 0–18 years.

There are translations in Spanish and Portuguese, with more languages coming soon.

Tip: Do not shy away from consulting with your users, even if this means talking about challenging and sensitive topics. You can learn so much that will help you to deliver the right information and support.

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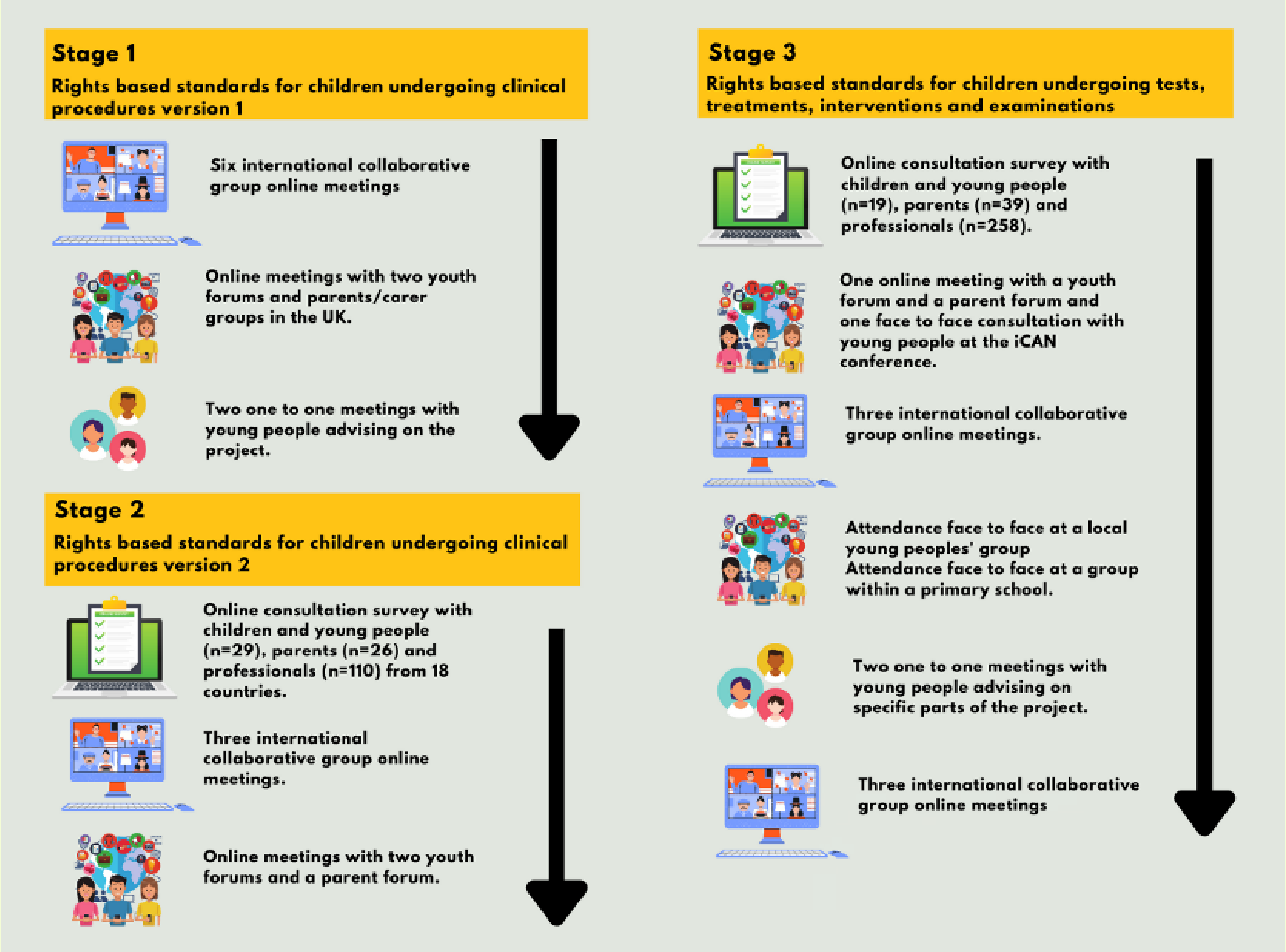
Children and young people were consulted and involved throughout the three-stage development process. The iSupport group invited feedback, input and consensus through two international surveys. Children and young people continue to be involved as further resources and accessible versions are developed.

Details of the three-stage development and consultation process can be seen on the iSupport website.

User comments include:
"The psychological wellbeing of a child before, during and after a procedure needs to be protected. This project will hopefully help do that and will avoid the unnecessary restraining of children for procedures."

Visit **isupportchildrensrights.com**



Stage 1
Rights based standards for children undergoing clinical procedures version 1

Six international collaborative group online meetings

Online meetings with two youth forums and parents/carer groups in the UK.

Two one to one meetings with young people advising on the project.

Stage 2
Rights based standards for children undergoing clinical procedures version 2

Online consultation survey with children and young people (n=29), parents (n=26) and professionals (n=110) from 18 countries.

Three international collaborative group online meetings.

Online meetings with two youth forums and a parent forum.

Stage 3
Rights based standards for children undergoing tests, treatments, interventions and examinations

Online consultation survey with children and young people (n=19), parents (n=39) and professionals (n=258).

One online meeting with a youth forum and a parent forum and one face to face consultation with young people at the iCAN conference.

Three international collaborative group online meetings.

Attendance face to face at a local young peoples' group
Attendance face to face at a group within a primary school.

Two one to one meetings with young people advising on specific parts of the project.

Three international collaborative group online meetings

An illustration from the iSupport website showing the development process

Young carers

In the UK, the Children's Society estimates there are **around 800,000 young carers** aged 5 to 17 looking after parents or family members with disabilities, physical or mental illness, or substance abuse problems.

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, and need more support to look after their own wellbeing.

They need information tailored to their age and level of understanding. You can find a comprehensive library of resources for professionals and young carers at **youngcarer.com**

Social prescribing

The NHS Plan highlights the need for information to help combat the continuing **rise in youth violence**.

Different health and other support services are urged to communicate better with each other and to deliver a consistent message to the public – especially children and young people.

The plan advocates more **integrated approaches, such as 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.

It uses resources from a wide range of sources in a local area such as education, health services, social services and the voluntary sector.

Information resources for children and young people are a potentially valuable tool for social prescribers tackling the rise in youth violence. For instance, the **Growing Against Violence J Dollar Gang Animation**.

Using music to improve public health outcomes in Sussex | Case study | AudioActive

AudioActive is a Sussex based charity that uses music as a vehicle to reach some of our county's most vulnerable young people.

In 2018 Brighton was identified as having one of the highest rates of teenage smoking and drinking in the country. Violent crime involving young people had risen across Sussex, with Brighton one of the worst affected areas.

With funding from Public Health and the Home Office (VRU), Audio Active launched SHIFT - a 12-week, 1:1 mentoring programme for young people – in Brighton. Designed to use music as an intervention tool at a crucial time in a young persons' life, SHIFT has now expanded across Sussex, including Crawley and Worthing.

SHIFT is adaptable and works in a variety of settings – schools, AudioActive's own studios, Pupil Referral Units and community centres. Young people can be referred by a variety of different professionals from a number of institutions.

Young people meet once a week with a mentor and build a trusting relationship, based on a shared passion for music. The mentor helps them achieve goals they set together based around music, building resilience and wellbeing outcomes.

SHIFT focuses on three main outcomes:

- Reduced risk of exclusion
- Improved mental health and wellbeing
- Increased resilience (and subsequent reduction in risk of violence vulnerability and exploitation).

Outcomes are measured through a combination of scaling questions, feedback from the young people themselves and their families and professionals and case studies. Here is some powerful feedback from people involved with SHIFT.

1. Reduced risk of Exclusion

YP: "I get in less trouble now; I find myself less angry with teachers. In my old school, the littlest things would get me in isolation."

School feedback: "This is such a positive aspect of his education and has given him a renewed energy in getting back into school. This is the first time that I have seen him enthused. Since beginning the project, we have seen an increase in attendance to school."

case study contintues on the next page

Professional feedback: "The work from AudioActive has played a huge part in the significant improvement we have seen from a vulnerable Year 11. We would make it to the end of Year 11, he is now determined to study music at college. It has been transformational."

2. Improved mental health and wellbeing

YP: "Music helps with my bad habits. It improves my mental health and stops me from hurting myself."

Parental feedback: "It has really boosted her confidence, she is learning new things and she has an outlet for her mental health with people that she trusts and I've never seen her so connected with anything - I am amazed by how successful it has been."

Mentor session feedback: "He has done really well and come a long way since we started. I feel like he has tried to elevate himself from a downtrodden mind state to a place where he can explore his surroundings and find himself a bit. Hopefully, the mentoring has been a good tool to assist him in this process."

3. Increased resilience of young people (and subsequent reduction in risk of violence vulnerability and exploitation)

YP: "Music is keeping me out of trouble with the police. I got into a lot of trouble and arrests. This has helped keep me away from my bad habits."

Parental feedback: "He has seemed a lot happier in himself and much more confident. We are both really grateful for this positive change in his life. He was quite at a loss and making some poor decisions before coming."

Visit **audioactive.org.uk**

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Chapter two: Health inequalities

Key points

- Unaddressed health inequalities can lead to lifelong disadvantage.
- Accessible health information can be part of a prescription for change, helping to reduce health inequalities.
- Using accessibility techniques will help ensure your resources reach a wide range of children and young people.
- There are many ways to improve accessibility. They can often be used alongside each other.
- Plan ahead to help get your resources to groups with known health inequalities. These groups need specific attention to make sure they are reached.
- There are legal as well as ethical reasons for ensuring people with disabilities can use your resources.
- A growing proportion of children in the UK do not have English as a first language.
- Failing to account for cultural and context sensitivities can be a barrier to accessible health information.

Why consider health inequalities?

The Royal College of Paediatrics and Child Health defines health inequalities in children and young people as:

"The avoidable, unfair and systematic differences in health outcomes between different groups of babies, children and young people. The drivers of health inequalities are the social, economic and environmental factors… that have an impact on their health outcomes. This includes ethnicity, income, housing, climate change and being looked after by local authorities."

Poverty is one of the biggest factors to create health inequalities, with challenges such as:

- Poor housing with inadequate heating and problems with damp and mould
- Poor environments for making lasting attachments, potentially leading to mental health challenges
- Poor quality childcare
- Low educational attainment
- Poor nutrition
- Lack of exercise.

Without intervention, disadvantage can carry on to cause lifelong poor health and low levels of wellbeing.

Accessible, understandable health information can help to reduce health inequalities, acting as part of a prescription for change.

Conversely, by not making health information more accessible to children and young people, healthcare workers and service providers are **failing them**.

In a 2023 NHS Youth Forum report, **more than 1 in 10 young people said they had felt discriminated against by NHS staff when accessing healthcare**.

They felt this was because of personal characteristics such as race, gender and disability.

Addressing challenges of social deprivation with Beano Studios

Case study | Royal College of Anaesthetists and Beano Studios

The Royal College of Anaesthetists (RCoA) and the Association of Paediatric Anaesthetists of Great Britain and Ireland have partnered with the Beano Studios to help children get operation-ready.

Featuring Beano comic characters Dennis and Gnasher, a comic strip tells the story of Dennis having his tonsils out.

It is supported by other challenges to help children get fitter for surgery.

RCoA's information lead Samantha Black is Consultant Paediatric and Perioperative Anaesthetist at Medway Foundation NHS Trust. Medway has 37 neighbourhoods ranked in the 20% most deprived areas nationally. 14 of them are in the 10% most deprived areas nationally.

Children from deprived backgrounds are twice as likely to live with obesity.

"**24% of children presenting for surgery are either overweight or obese**, and many have severe tooth decay," says Dr Black.

"Coming for an operation is a real moment to make every contact count. Parents are concerned about surgery and very motivated to help their child get fitter for it.

"We hope that providing this information is a moment of change."

Dr Black chose Dennis because he is a well-known character with a TV show and a sell-out print comic.

The comic strip is an accessible and engaging way to provide information, particularly for children who struggle with reading.

It comes with a separate sheet of tips for getting healthier, a reward chart and stickers. It is supported by online challenges.

A Cub Scout group and primary school helped develop the comic with RCoA and the team at the Beano.

Download the comic and other resources at **rcoa.ac.uk**

Discrimination can also lead to health inequalities. A data review by the **Association of Young People's Health** identified the following:

Mental health – Black young people are 10 times more likely to be referred to CAMHS via social services, rather than via the GP, compared to White young people.

Vaccination rates – Chinese young people aged 12-15 were 6 times more likely to receive the Covid-19 vaccine compared to both Gypsy Roma and Black Caribbean young people.

Hospital admissions – In 2020/21, 10.4 per 100 Black young people aged 10-24 were admitted to hospital, compared to 1.7 per 100 Chinese young people.

Racism, micro-aggressions, language, lack of representation and lack of trust were identified as barriers by AYPH's Youth Panel.

Report puts focus on reducing health inequalities

A 2023 review of the effectiveness of local ICSs says they need more autonomy to help them address health inequalities.

The **Hewitt Review: an independent review of integrated care systems** has many suggestions aimed at ICS delivery of four core principles:

- Improving health outcomes and services
- Reducing health inequalities
- Delivering a financially sustainable health and care system
- Supporting social and economic development of local communities.

All children and young people are entitled to their own health information as a matter of ethical principle (see Chapter 1, page 15).

Make sure you are catering for everyone in your target audience, including people and groups likely to be experiencing health inequalities.

Tip: Plan ahead to help get your resources to those that need them.

For instance, radio stations aimed at particular sections of your target audience, such as **BBC Asian Radio**.

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) such as hearing loss or impaired vision. Autistic children and young people and those with ADHD can have particular accessibility needs.

Remember...

To check the Core20 health inequalities list on page 15

Different groups have different needs

Find out about the general characteristics and accessibility needs of your target audience when planning health information. The aim should be to make information accessible to all.

For instance, children in care and young care-experienced people are likely to be part of the target audience for any health information for children and young people, but:

- More than **80% of children in care have special educational needs**
- 35% have an Educational Health Care Plan
- **50% meet the criteria for a possible mental health disorder**
- **26% of homeless people have spent time in care**.

Think about how you use language around family and background.
Do not assume a stable and consistent home.

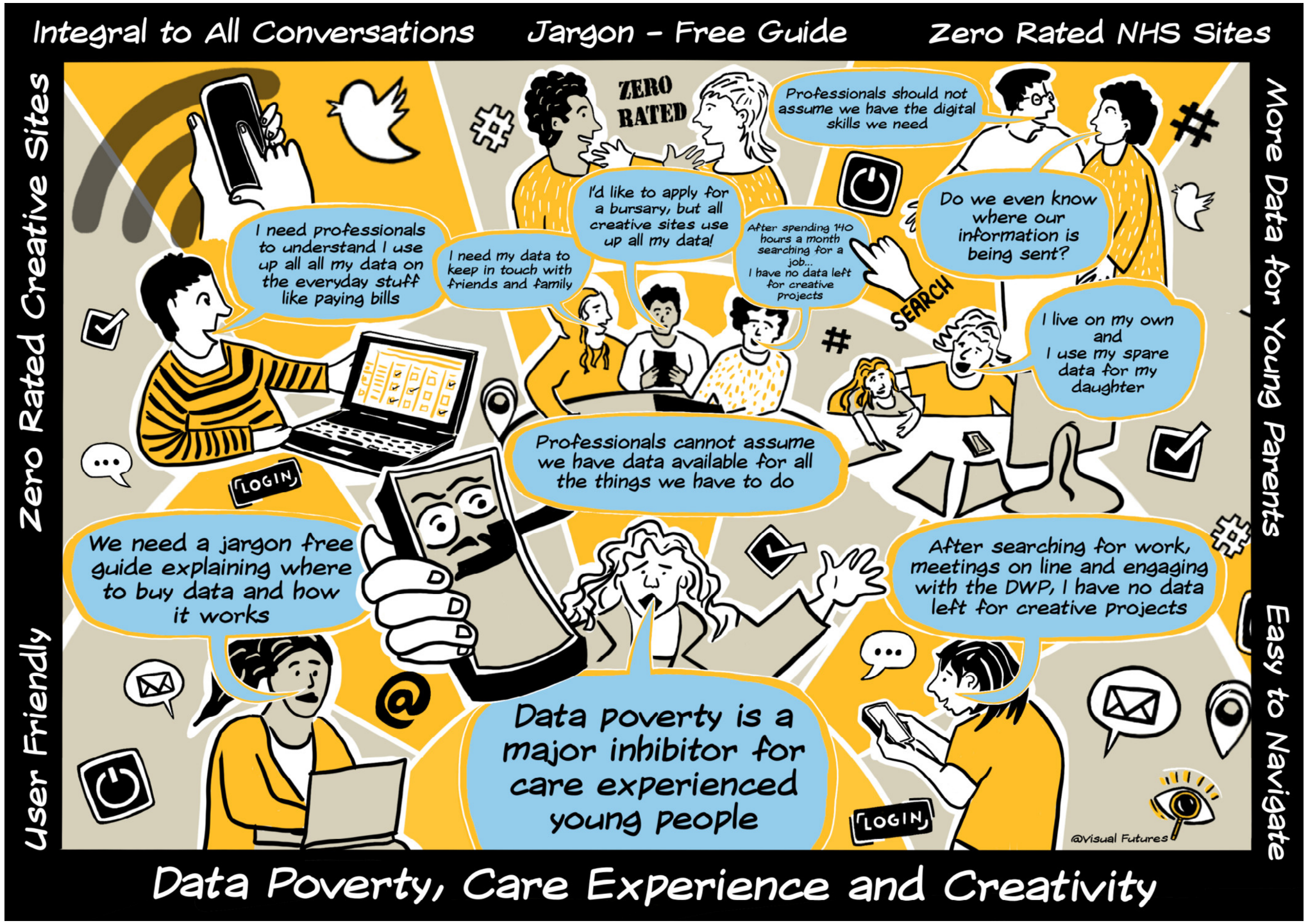
Health and digital literacy challenges exclude millions of people from finding and making effective use of reliable health information. This inevitably leads to health inequalities.

These challenges may affect anyone at any time. It is not simply linked to educational attainment or socioeconomic status.

Anyone's health and digital literacy levels can be affected by factors such as the stress of a serious diagnosis.

Remember to cater for accessibility needs of families, friends, other trusted adults and healthcare professionals. Health information for children and young people needs to include supporting information or resources for these groups.

Data poverty is one factor preventing young people from using digital healthcare tools.



Co-created by young people, this image focuses on data poverty as an excluding factor from digital creative projects. The data poverty barrier applies equally to digital health information.

Young care-experienced people in particular often experience data poverty and exclusion from many aspects of online life.

To help remove this barrier, think if you can make your digital resources for children and young people data light.

Young care-experienced people often lack the support to be knowledgeable users of websites and social media. This leaves them vulnerable to online harm.

Catch 22 provides more information about children and young people, and social media and internet access.

PIF's 2023 Health and Digital Literacy Survey Report makes good practice recommendations.

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

There are training and educational resources on health and digital literacy available online.

For instance, NHS England and Health Education Scotland have together produced a variety of **health literacy resources and courses**.

The Health Literacy Place also has a **health literacy toolkit**.

PIF offers CPD-accredited **health and digital literacy training**.

PIF Health and digital literacy survey 2022/23

Accessibility and clinical guidelines underpin award-winning television show

Case study | Operation Ouch! and Maverick Production House

Operation Ouch! is a BAFTA award-winning medical entertainment show for children and their families and carers. It airs on the **CBBC channel** and **YouTube**.

Awareness of NHS guidelines is an underlying principle for the producers and presenters of Operation Ouch! This applies equally to accessibility and clinical conditions or topics.

With sign language, audio descriptions and subtitles available, the show presents examples of chronic diseases and medical situations in a sensitive and matter-of-fact way. It demonstrates children and young people can continue to have a good quality of life even with long-term, life-changing diagnoses.

There are **Operation Ouch! games** and **YouTube video channels in different languages**.

The show's presenters include two sets of twin doctors, Drs Chris and Xand Vantelluakn and Drs Dan and Raph Olaiya, as well as Dr Ronx. They team up to take viewers on a journey through medicine via experiments and the lived experiences of patients.

Content for the show is created using these steps:

- Scoping to understand what the audience wants to know about a topic. For instance, childhood leukaemia.
- Defining the aim of the item. For example: to educate on leukaemia by explaining what it is, how it is treated and how people live with it.
- Research using trustworthy sources such as the **NHS website** and **patient.co.uk**
- Involving clinical specialists in the show to discuss the topic and review content for accuracy.
- Letting patients, family and carers review their recording to ensure they are happy with it being broadcast.

Tip: Focus on combining information with age-appropriate, engaging stories and concepts.

The importance of making text and images accessible to screen readers

Alternative (alt) text explains an image in relation to a document or webpage.

It is read aloud by screen reader software to help people with visual challenges access and interact with digital resources.

It is indexed by search engines and may help people find your resources.

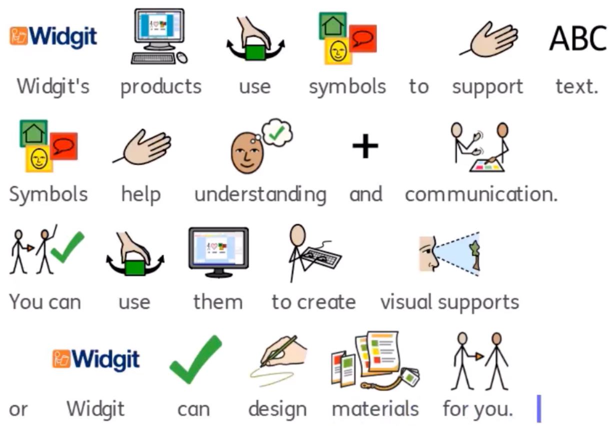
Alt text should be added to all non-decorative images. Keep it short and descriptive.

Text in PDFs should be tagged to make it accessible to screen readers.

More advice on meeting accessibility guidelines is available in PIF's **Web accessibility – a quick guide**.

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

Visit Widgit at **widgit.com**



Widgit's products use symbols to support text. Symbols help understanding and communication. You can use them to create visual supports or Widgit can design materials for you.

Talk and play

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 starting 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 **evelinalondon.nhs.uk**

The Equality Act

Under **The Equality Act** (2010) it is unlawful to discriminate against a disabled person. This includes offering a service that is not as good as one offered to a person not classed as disabled.

It is the responsibility of each organisation to take 'reasonable' steps to provide information in an accessible format. For instance, including visual communications, providing Braille and large print versions and, with video, adding subtitles and British Sign Language (BSL) translation.

Tip: Information that is accessible for an autistic person or someone with ADHD may work for everyone. This is not true the other way round.

Some children and young people with disabilities will have severely limited scope for making decisions. At the same time, they are likely to have more medical interventions than other children.

Make provision for audiences with:

- Hearing loss: Include visual communications and, when using videos, arrange subtitles and 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, NHS Accessible Information Standard and the **Macular Society** publish guidelines.
- Speech, language and communication needs: The children's communication charity, iCan, offers information and advice at **ican.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 the **European Agency for Special Needs and Inclusive Education**.

NHS Accessible Information Standard

Guidance on accessibility in health and social care settings came into force in August 2016. The standard was under review at the time of writing, with publication long anticipated.

You can find the standard and supporting documents at **england.nhs.uk**

Languages other than English

A growing proportion of children in the UK have a first language other than English. In 2021, **according to government statistics**, this applied to nearly 1 in 5 children in schools in England.

Depending on the geographic range of your information and services, it may be particularly important to think about the language and communication needs of Welsh speakers.

Many people in Wales can only communicate and participate in services as equal partners in their first language of Welsh.

As with other languages, best practice is to produce bilingual editions of resources so English-speakers can understand and help to disseminate the information.

Using clear, plain language improves understanding for everyone using your material. It can be particularly helpful when your audience does not have English as a first language.

PIF members can access its guide to **Using Plain Language in Health Information here**.

If you are planning to produce translations, involve young people from relevant communities early on. If you are using machine translation on your website include a disclaimer about clinical accuracy.

Guide to translating health information

PIF has a guide to **translating health information** for its members.

It was updated in 2022 to include new technologies such as machine translation.

While it is mainly focused on foreign language translation, the principles can also be applied to British Sign Language and Braille.

Cultural sensitivity and diversity

Being culturally sensitive means taking into account the background, beliefs and values of your audience. You should also be aware of any potential cultural barriers that could affect a child or young person's understanding of the information.

The diversity of children and young people in the UK continues to increase.

Healthcare services are increasingly working with different customs and languages from diverse groups.

Ways to develop more culturally competent healthcare information include:

- Building the respect of people from other cultures
- Reaching out to understand the world from another's point of view
- Embracing ambiguity
- Having a desire to learn.

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.

An area where language and attitudes are developing quickly is the LGBTQ+ community.

Young people are now more likely than in the past to be open about questioning their birth-assigned gender or their sexual identities. Many have strong views about the language used and inclusivity of these differences in health information.

The charity Stonewall keeps up to date with the use of language in this sector, which is still developing. You can find a **list of LGBTQ+ terms on its website**.

At every stage of your project, remember to check out your own perspective.

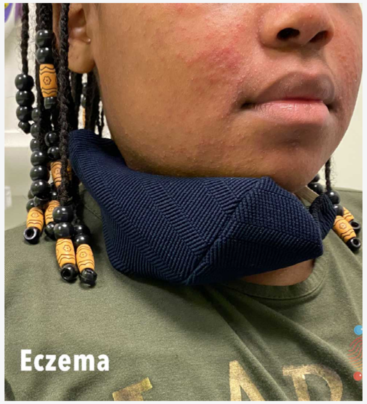
It helps to write down your personal views on issues like gender, sexual orientation, race, social class, age and even politics.

Ask yourself how others' views might differ and how this could be addressed in your resources and work.

Free skin tone resources

Skin Deep offers a free bank of high-quality photographs of medical conditions in a range of skin tones.

This is via a collaboration between the international medical education team Do Not Forget the Bubbles and the Royal London Hospital.



Visit **dftbskindeep.com**

It is important to think broadly and do your best to ensure the information can reach a wide range of children and young people.

Accessible, developmentally appropriate, culturally-sensitive healthcare information can help bridge societal barriers, helping significantly to improve child health outcomes.

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.

Collaboration aids cultural sensitivity

You can access translated health information on the Migrant Information Hub, **Navigating the NHS: a Resource for Asylum Seekers and Refugees**.

It has been created collaboratively by multiple agencies with everyday experience of dealing with different cultures.

But little of this information is specifically for children and young people.

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Chapter three: Involving children and young people

Key points

- Consulting with stakeholders and your target audience from development through to evaluation will make your information relevant and well targeted.
- Greater involvement makes your resources more credible.
- Involving children and young people can aid dissemination and use of resources. Peer advocates can be incredibly powerful in sharing information.
- Health information is about service developments that enhance communication as well as information resources.
- Done well, consultation experience benefits children and young people because they gain confidence, feel valued and learn their opinions matter.
- Scoping work is essential to understand your audience and ensure involvement is representative and inclusive.
- Take care to involve children and young people representing groups who might need greater focus to identify and engage.
- Working in a meaningful way involves time and creativity.
- It is important to act on input while being transparent about the limitations of a project.
- A clear safeguarding policy is compulsory.
- Remember to thank children and young people with a letter, prize or certificate, share the end results and share what you changed as a result of their involvement.

The case for involvement

Informed choice has become a cornerstone of UK health policy, alongside public participation in planning and improving services.

The guiding principle is people having control over their own health. To do so, they need high-quality information. These principles apply to children and young people just as much as to adults.

The seminal **Children and Young People's Health Outcomes Forum** was at work between 2012 and 2015. It 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 partner organisations pledged to increase efforts to involve young patients and their families, and improve care.

In 2013, the **NHS Youth Forum** was set up to give young people a say in health services.

Another consultation found young people want to understand the different services primary care can provide.

NHS Youth Forum reports

More than 20 young people make up the NHS Youth Forum. They carry out research projects each year. In May 2023, they published four reports:

- Health literacy: A review on how to make NHS information more accessible to young people
- NHS Youth Forum: Healthcare inequalities
- Digital access report
- Young people's mental health experiences.

In its recommendations, the Health literacy report emphasises the importance of consulting young people about social media.

It found an NHS Instagram offering would be well received by teenagers and young people: *"The evidence… supports the establishment of an NHS Instagram specific to children and young people [CYP]. To begin with, we suggest one CYP-specific post on the NHS Instagram a week… We recommend expanding the CYP board's reach to have someone as a permanent member of the NHS social media communications team. They should be involved in the ideation and revision of communications."*

The healthcare inequalities report suggests involving more people of all ages from marginalised groups in training and service development.

The digital access report includes a 'design brief, by young people, for young people' for an improved NHS app.

Recommendations from the mental health experiences report include co-production of services and information with experts and young people with lived experience.
You can download all the reports from the British Youth Council website **here**.

PIF TICK: Look out for the big green tick

Trusted Information Creator

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 involving users in the production of health information to help make sure it meets an identifiable need, and is easy to use and understand.

PIF TICK members who meet the standards can display a big green PIF TICK. This helps people identify the information as trustworthy.
Visit **piftick.org.uk**

A study from 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 and their parents, using a survey, interviews, focus groups and direct experience recordings.

It demonstrated widespread use of digital technologies among young people wanting information about a healthy lifestyle. But they still relied heavily on trusted adults to help them resolve worries about privacy, how to find trustworthy information and making sense of data among a growing pool of information sources.

The study found children and young people valued accreditation from trusted sources such as the NHS and Bupa.

These findings highlight the value of involvement and consultation when producing health information.

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
- Help identify your target audience more clearly
- Offer new insights for professionals working with children and young people
- Help young people learn about their own health
- Build their confidence and self-esteem
- Show children and young people that their opinions, ideas and experiences matter
- Prove that they really can make a difference.

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

PIF members can view a guide on involving users **here**.

Remember…

To check the Core20 health inequalities list on page 15

Increasing impact through involvement | Case study | Partnership for Young London

Given the serious impact the COVID-19 pandemic was having on young Londoners, the **Partnership for Young London** wanted to produce impactful information for policy-makers to highlight the problems and potential solutions.

This led to the **Mapping Young London project**, joined by 22 organisations.

The project had co-design and collaboration at its heart. It used a survey and focus groups, with questions co-designed with groups of young Londoners.

Researchers spoke to more than 1,600 diverse young Londoners aged 16–25.
Questions revealed a range of lived experiences, from refugees and migrants to people with experience of homelessness or insecure housing.

The introduction of the report, written by 16-year-old Jane D'Ornellas, highlights this diversity:
"It is… interesting that while young people have different priorities, there is one thing that they all seemed to agree on: that the best thing about living in London was the mixture of people.
"The issues are clear for young Londoners, they want affordable housing, a job that they want to wake up to do, and support for their mental health and wellbeing."

Among the key findings of the study is evidence of the mental health crisis among young people. More than 1 in 3 of the young Londoners surveyed reported wellbeing scores indicating depression.

partnershipforyounglondon.org.uk

Tip: The more stakeholders you involve and collaborate with, the greater the credibility of your resources.

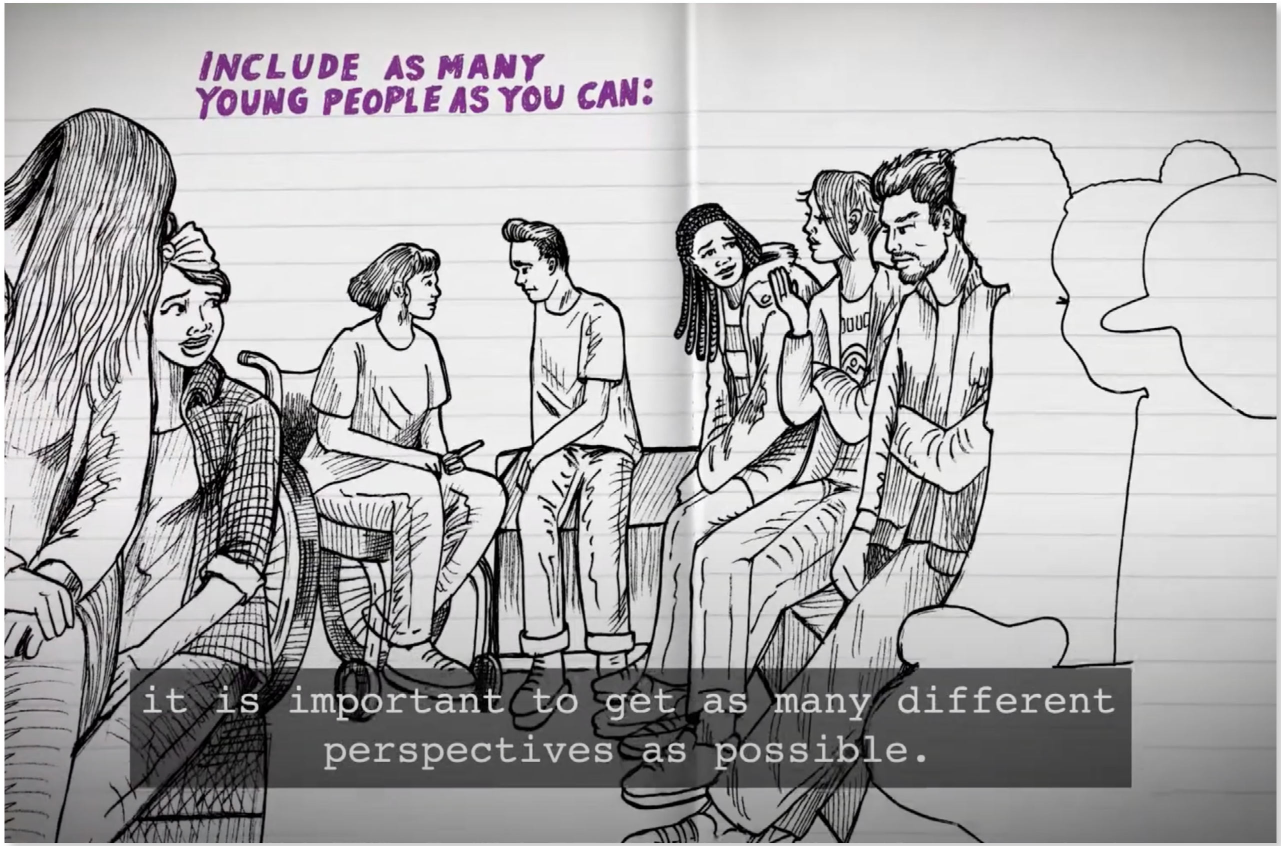
Involvement in developing services

Altogether Better is a youth-led charter developed by 240 young people across England.

It outlines what young people expect from their mental health and wellbeing services.

A film available on YouTube shows how **membership organisation Youth Access** supported the production of the charter. It includes tips on how to involve young people in service development.

View the film at **www.youtube.com**



Connecting with children and young people

Children and young people are not a homogeneous group. It is important to identify and engage the most excluded as they may need your information the most.

Consider their particular needs and involve them in the development of information.

Two reports from the No Child Left Behind project have identified a number of vulnerable and potentially excluded groups.

According to the **National Children's Bureau** and **Public Health England** in **A public health informed approach to improving outcomes for vulnerable children** and **Understanding and quantifying childhood vulnerability** these include people:

- In younger age groups
- From minority ethnic backgrounds
- Living in disadvantaged households
- In public care
- In the youth justice system
- Who are refugees or seeking asylum
- Who have a disability or special needs
- Who are gay, lesbian or transgender
- Who are teenage parents
- Who have long-term health needs.

It is vital to include children and young people who share the attributes or experiences of your target audience. Remember some young people will face a combination of challenges.

Look for facts such as population statistics. For instance, if you are targeting childhood obesity, look at prevalence and trends according to age, gender, ethnicity and socioeconomic factors.

Do the same for the geographical area you plan to cover.

Look for the facts on your topic and geographic area

The Obesity Health Alliance is a group of more than 50 health charities, campaign groups and medical royal colleges

It says overweight and obesity is high across the UK population.

Its **Health Inequalities Position Statement** says associated inequalities are growing. The statement reveals:

- Children from deprived groups are more than twice as likely to be living with obesity
- Black and Asian children have higher obesity rates than the national average
- People with learning disabilities are much more likely to be living with obesity.

An approach to consultation

With efficient scoping in advance, it will be easier to make sure you are including a wide range of views and experience when you are engaging with children and young people.

Share the results of your scoping work.

- Ask children and young people what they think is needed
- Develop drafts and seek feedback

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

- Would you use it?
- Do you think there is anyone who would find it hard to use or understand?
- What do you like about it?
- What do you dislike about it?
- What needs to be better?
- What's missing?
- Which words do not make sense?
- What do you think of the colours?
- What information needs adding?
- What do you think about the pictures?

You can also give them simple tasks such as: 'Can you find the bit where it talks about…'

Tip: During activities start with fewer questions and have a couple of backups if time allows.

Do not overestimate how many questions can be answered in the allocated time.

Remember to make activities accessible to all.

Connecting with traumatised children and young people

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

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

An interaction most may see as neutral or therapeutic may not be taken that way. For instance, a lanyard can carry negative associations for children and young people who have had interactions with social services or the police.

Looked after children, including refugees and asylum seekers, may be particularly likely to suffer from trauma. This may include physical and sexual assault, and separation from their families.

If your target audience is likely to be affected by some of these issues, there are some key points to keep in mind.

- Keep the important information clear and to the point
- Think about why this young person needs to know the information
- Consider platforms such as YouTube, TikTok and Instagram
- Respect the maturity-beyond-years of some children and young people, but also realise they might nevertheless struggle to read large blocks of text or formal information
- Consider different ways of presenting the information, such as a credit card-sized leaflet or a plastic card wallet
- Think about who your target audience turns to for advice or further information. For instance, local youth services.

Trauma informed care
Dr Sveta Alladi, the Named Doctor for Looked After Children in the London borough of Newham, says of the young refugee and asylum seekers coming into her care:

"The approach you need is trauma-informed and culturally sensitive because there are certain things many of them cannot do, will not have understanding of, or which will be triggering.

"'They may not want to expose their skin [in face-to-face settings] because they've got marks they do not want people to see."

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 a person who challenges their perception of professionals.
- Discuss information in private, allowing space for questions to be asked. Children and young people have the right 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.
- Do not make promises you cannot keep.
- Set time frames for treatment or recovery. If a young person needs to come back to a clinic or GP at 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?

Finding collaborators

Your organisation may already work closely with a broad range of children and young people.

For instance, NHS Trusts will have a Members' Council or Young People's Forum.

Other organisations may be able to help you find children and young people willing to advise on your project. They could also help you expand your existing pool of children and young people for wider representation.

Try contacting schools, NHS organisations, your local ICS, youth organisations, faith groups, voluntary groups, and charities for children and young people.

All of them will have many other priorities, so try to fit your work in with them. If relevant, mention how your work might help to meet their objectives.

You may have to provide reassurance about the process and quality standards. Organisations are rightly protective of the children and young people they work with.

Involvement to create relatable and engaging resources | Case study | Cystic Fibrosis Trust

The Cystic Fibrosis Trust identified a need for a fun, interactive way for children with cystic fibrosis (CF), their friends and siblings to understand the condition.

It created a new resource, with help from affected children, their families and healthcare professionals.

The resulting activity pack and film has voiceovers from children with CF or who have a sibling with CF.

It also has film characters designed by children taking part in a co-production competition.

The 'design your own character' contest involved children from the CF community and produced 2 of the resource characters, Layla and Huffin.

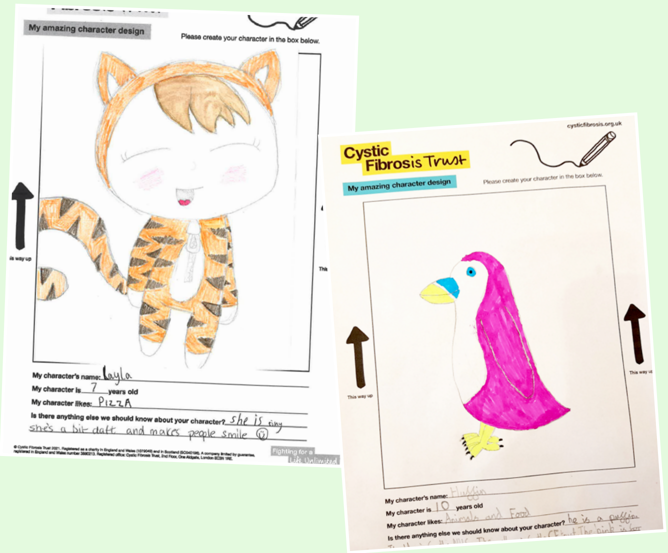
The Trust wanted children to be able to see themselves in the new resources, reducing stereotyping through positive representation. The new characters represent a range of experiences in health and treatments.

Research carried out with siblings of children with CF revealed they needed more support to understand their brother or sister's condition. The film features characters who have a sibling with CF.

The launch of resources on Instagram, Twitter and Facebook in July 2022 received enthusiastic responses.

By March 2023, the film had been viewed almost 15,000 times.

To see Layla and Huffin in action or download the activity pack, visit **cysticfibrosis.org.uk**



My amazing character design

Please create your character in the box below.

My character's name: Layla
My character is 7 years old
My character likes: PIZZA
Is there anything else we should know about your character? she is tiny she's a bit daft and makes people smile ☺

My amazing character design

Please create your character in the box below.

My character's name: Huffin
My character is 10 years old
My character likes: Animals and Food
Is there anything else we should know about your character? he is a puffin.

Tip: Meaningful involvement is key. Let children and young people shape the project with you, with enough time for them to give you feedback at every stage. They will have the best insights, and fresh, creative ideas on what will work best to engage their peers.

Points to remember when involving children and young people

Children and young people need to be involved in a meaningful way. Be honest about how much influence they will have.

Set clear objectives so the children or young people know what their contribution will achieve.

Working with children and young people needs sensitivity and flexibility, especially if they have serious health problems or face health and digital literacy obstacles.

Some people may not want to be involved, or have a change of heart along the way. Be prepared to be guided by the child or young person, their parents or carers, and the professionals looking after them.

What works well for one person may not suit another. Some children and young people enjoy group discussions and activities. Others feel more comfortable on their own. Some like reading and writing. Others do not.

Professionals must create ways for children and young people with communication, learning and language differences to share their views.

Digital media are popular with many children and young people, but do not assume everyone feels confident in or has access to a digital world.

16% of 18-25s have no access to a laptop or desktop computer

2 million UK households struggle to afford internet access

There can also be safeguarding issues.

A 2022 Good Things Foundation survey found **almost 1 in 4 black and minority ethnic users had faced potential online harm in the past month**.

Your approach needs to be appropriate to the age group. Make things fun and interesting. Use drama, puppets, role-play, music, games, competitions, 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.

Consider offering alternative ways for children and young people to get involved. Ask people to put questions they were afraid or embarrassed to ask on Post-it notes and stick them on a wall.

The facilitator should make clear they do not mind bad writing or spelling. Children and young people can get embarrassed about those things too.

With discussions and activities, smaller groups often work best. Be aware of peer pressure, which may cause some children or young people to withdraw or give false opinions. Consider providing some one-to-one time.

A facilitator not involved in the care of the children or young people, or in producing the information, can help children and young people feel freer to give their honest opinions.

Tip: Listen carefully to what the children and young people want – it might be different to what you think they want.

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

- Provide a safe and comfortable environment in a community setting
- Highlight the importance of confidentiality and boundaries
- Use music and provide refreshments
- Plan short sessions out of school hours or in school hours with the support of teachers
- Provide help with travel arrangements
- Make sure expenses are covered
- Accommodate any special needs or disability
- Have someone available to support anyone who becomes distressed or unable to cope
- Have a private area where people can go if they are struggling
- Consider using video links so people unable to travel to the venue can still take part.

Safeguarding children

Everyone who has contact with children has a duty of care, so your organisation must have a clear safeguarding policy. For information and advice, **visit the NSPCC**.

Online forums, meeting apps, emails and online surveys can also be useful. Remember, some children and young people may be digitally excluded.

Let children and young people know you value their contribution. For instance, via a note from the chief executive, certificates or prizes.

Payment can be problematic if the activity was carried out at school or affects a family's benefit payments. Vouchers are usually welcome and do not affect benefits.

Share the final result with your group, and explain how their input made a difference.

Safeguarding and supporting young people | Case study | Mind

Self-harm is a complex, emotive and potentially triggering topic, Mind took a sensitive and bespoke approach to planning the engagement for a new information product (see page 14 for more details).

Mind aimed to involve as many young people as possible, work with them in a way that felt most safe and comfortable for them, and ensure the right support was in place.

Mind advertised the opportunity to its Youth Voice Network, explaining different ways people could get involved.

After reviewing young people's expressions of interests and demographic data, Mind planned groups with activities based on respondents' preferences and experiences. These included focus groups, interviews and email reviews.

Invitations for an initial phone call were sent, with leaflets signposting to websites, helplines and support for self-harm.

There were 2 Mind staff on each of the calls. These calls aimed to hear more about young people's journeys, how they'd like to work with Mind and what support they needed. A staff member led the conversation while the other monitored wellbeing and safeguarding.

Each young person taking part filled out a consent and information form containing a mental health and wellbeing action plan.

Two Mind staff were present during interviews, one leading the discussion and one monitoring wellbeing while taking notes. For the groups, two Mind staff facilitated and took notes, while a third monitored wellbeing and safeguarding.

There was a breakout room for participants if they needed a break or wanted to talk to the safeguarding lead. The safeguarding lead also used the private chat function to check on young people throughout.

Young people were invited to review drafts of the resources at various stages.

Mind sent all participants "You said, we did" feedback and vouchers. This helped young people to see the impact they had on the work. Mind also emailed participants **when the resources went live**.

Tip: Make time for initial calls or a pre-session meet up, especially for complex topics. The calls were invaluable, helping to build rapport with each young person and understand their support needs.

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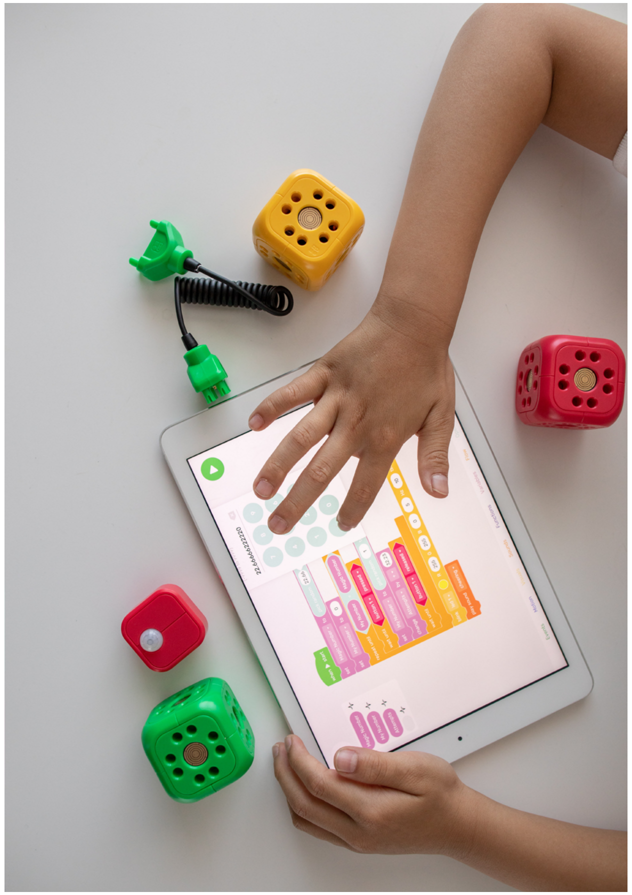
Chapter four: Communicating health information

Key points

- There are core principles of communicating health information that must be followed.
- Scope out existing materials popular with children and young people.
- Appropriateness to age and developmental levels is important.
- Involve parents, carers and other family members significant to the child or young person.
- Other young people can be effective communicators of health information.
- Teachers can be helpful to disseminate trusted information.
- Children and young people are heavy users of social media, but they 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.
- Always include clear signposting to more information, advice and support.



Getting started

General Medical Council guidance on communicating with children and young people emphasises it is always important to:

- Establish what they want and 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 crucial, although it can be hard to decide how much they need to know and when. Aim to be reassuring but truthful.

Do not make assumptions about knowledge and understanding. Check what the children and young people already know. They may have a misunderstanding of a long term condition.

Information and resources are often best discussed with the child by a healthcare professional during a consultation, if possible. Methods such as 'chunk and check' and 'teach back' can help professionals ensure they have communicated clearly.

People in general **prefer to receive patient information direct from a healthcare professional**. Parents expect HCPs to give them information rather than looking up information or reading leaflets themselves.

Make sure you involve healthcare professionals. Their invaluable experience may include suggesting effective ways to promote and distribute your resources.

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

Case study | Diabetes UK

My Life is a guide to type 1 diabetes designed to help children age 7–11 learn about their condition in a fun, friendly and engaging way.

It uses games, letters, mini stories and characters with diabetes.

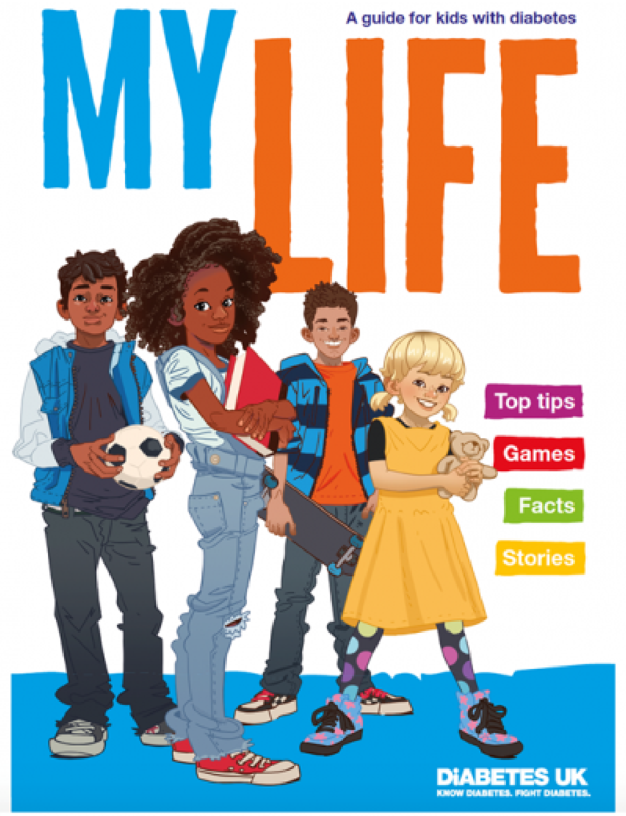
In 2020, insight from a user group of 16 children helped refresh the My Life characters based on current trends in children's media. The characters are different ages, have a variety of hobbies and diverse experiences of diabetes.

Children with diabetes and their parents or carers are part of a user involvement panel for My Life.

They contribute ideas for features, and review content for different sections, character illustrations and page designs.

This has led to some of them joining in with other areas at Diabetes UK. This includes sharing their stories in the Parent and Carer's Guide to Type 1 Diabetes and appearing in the Diabetes UK membership magazine, Balance.

Find out more at **diabetes.org.uk**



Tip: Your audience is children and young people. Any resource you design for them must meet their health needs and their expectations of information. You're 'competing' with commercial, fun products.

What works

There is a lot of health information for children and young people. But it is not easy to find out what works best just by searching academic papers because the evidence base continues to evolve and the **research is inconsistent**.

Children are not just small adults, and teenagers and young adults are not just big children. Past experience may shape the way children and young people understand and interpret information.

To produce resources at the right level for a particular condition, age group or health experience, it helps to look at 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.

Remember, most children's writing aims to stretch a child's vocabulary and comprehension skills. In contrast, writers of health information should keep the text as simple as possible.

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

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

Aim to work with a group with mixed abilities and needs.

Golden rules when writing for children and young people

☑ **Keep sentences short and in logical order.** "You will fall asleep after the injection" could read, "You will have an injection, then fall asleep."

☑ **Keep the vocabulary simple and explain new words.** Words can also be written phonetically. For instance, "It is called epilepsy (say: epi-lep-see)."

☑ **Numbers and statistics.** Terms such as "60%" may not mean much to many children. Consider saying "6 out of 10", or showing data as graphics.

☑ **Call attention to facts.** Devices like 'It's Amazing!', 'Did you Know?' or 'Top Five Facts' can highlight short, succinct and important details.

☑ **Big chunks of text are off-putting.** Break up text by using bullet points, different fonts, colours and pictures that add meaning. Place important text into boxes or use a bigger or bold font.

Think about 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.

☑ **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. For instance, when using the **teach back health literacy technique**.

There are automated tools that can check for readability. For instance, **Hemingway Editor** and the **SMOG readability calculator**.

These tools can only give a rough indication, so they need to be used alongside other techniques, such as user involvement and collaborating with experts.

Remember…

To check the Core20 health inequalities list on page 15

Camilla de la Bedoyere is an educator and author of more than 250 books for children. There are writing tips on her website. **Camilladelabedoyere.co.uk**

Life-saving messaging uses inclusive language for young people | Case study | CoppaFeel!

CoppaFeel! exists to create awareness of breast cancer among young people.

Its messaging aims to:

- Encourage young people to check their breasts and chests
- Educate them about signs and symptoms of breast cancer
- Empower them to take action should they notice anything unusual for them.

The charity's message needs to resonate with its target audience of 14–24-year-olds, and language is used to build connections which help to influence behaviours.

The tone of voice uses humour and personality to talk about a serious subject in a proactive and engaging way. It evolves as language that resonates with young people changes rapidly.

It is based on some core principles:

- Gender neutral terms
- Ordinary everyday words
- Clear, simple language.

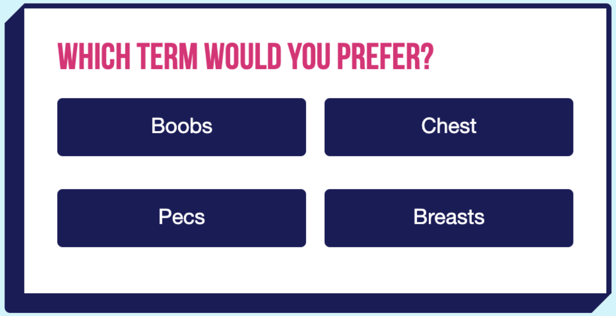
It aims to strike a balance between accurate health language and inclusive terminology.

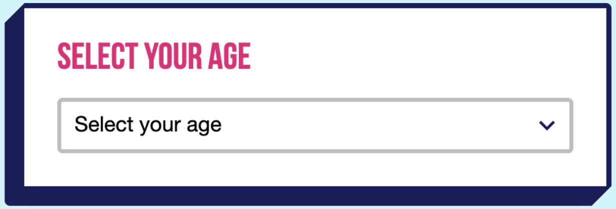
Research methods include:

- User focus groups to help develop messaging and resources
- Asking young people to test resources
- An Inclusive Change Advisory Group.

The charity aims to minimise barriers by using actively inclusive language. For example, the Self-Checkout web app was developed to encourage checking behaviour. It allows users to choose their preferred terms.

Visit coppafeel.org





Tip: Actively listen to young people's views and opinions.

Information for different age groups

To help ensure your information is appropriate to the age and maturity of your audience, it is useful to reference the learning stages used in schools.

However, remember children and young people with special educational needs, trauma and stress are likely to need information at a different level, while those experienced with a long term condition may need higher level information or have been exposed to misinformation about their health.

For instance, England's national curriculum uses:

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

Younger children

Children under 5 **learn and understand through play**. As well as talking to young children, you may want to use dolls or teddies or drawing activities. Younger children are also familiar with short animations and TV programmes.

Storybooks can help to explain what is happening or what to expect. The case study on page 70 from Crohn's & Colitis UK illustrates how this comforting and familiar format can work well, both in print and digital media.

According to **Ofcom**, smartphones and tablets are the most commonly used device for getting online, even among the youngest age groups.

in 2021

99%

of children went online

Ofcom

There is debate about the educational and developmental merits of digital media for very young children.

Between 5 and 7 years, children are developing memory and questioning skills. They love storytelling. Some can read independently and may be starting to use books and digital formats to find information.

They like a question-and-answer format. However, the spoken word, role-play and pictures are important, as 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.

If you are planning to use digital media, consider material that is designed for sharing with peers, teachers or parents.

Older children

Most children aged between [8 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 judgements and decisions.

This age group likes the question-and-answer format. They also enjoy 'amazing facts' or 'did you know?' features.

Design and visual appeal is crucial whether you are using traditional or digital formats. Images should be relevant and well captioned.

Stickers and reward charts are popular, but may not be suitable for some children and young people.

Families and schools are a good way to reach children of this age with support from trusted adults. Take time to involve children outside these settings.

Teenagers

By secondary school, most young people are:

- Learning to verify the accuracy and reliability of information
- Forming and expressing their own opinions
- Starting to detect bias
- Beginning to understand complicated concepts if they are explained clearly
- Searching for information online.

Digital formats can make sense because young people spend around **3.5 hours a day online**. Viewing online videos and playing games on the internet are popular activities. Social media is a part of everyday life for most.

Remember, not all young people can get online and some prefer traditional formats (see Crohn's & Colitis case study page 70).

Question-and-answer formats are good for communicating facts, myth busting and addressing worries. Personal stories are important for making information relevant.

Peer-to-peer communication is powerful, and many organisations offer support networks for young people.

For young people with long-term conditions, **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.

Gentle learning for children affected by motor neurone disease

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. Without explanation, they may feel isolated or think they are somehow to blame for the way things are changing.

The MND Association helps children learn about the disease in a gentle way. It uses stories, games, activities and sharing of creative writing and artwork. This is via a web-based hub.

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.

Feedback surveys, monitoring of social media responses, download and order data are all collated to ensure development continues in the right direction.

View the resources at **mndbuddies.org**

Sensitive subjects

Health information can cover sensitive, frightening or upsetting subjects. Where the child or young person is seeking information about someone they love, they might be afraid that the person will die. They may need support from a bereavement organisation.

Young people, teenagers in particular, can be crippled by embarrassment over topics that might not appear sensitive at first.

For instance, GPs have reported some young people leaving their athlete's foot for months before coming for treatment because they are embarrassed.

It can be helpful to warn the child or young person that material might be upsetting. This prepares them emotionally and means they can choose to read it with a supportive adult or friend.

Try to keep terms, vocabulary and explanations consistent. This is both within the resource and with other information the child or young person is likely to be given. This is especially important for sensitive subjects where the young person may feel uncomfortable seeking clarification or euphemisms are often used.

Other ideas include:

- Ask for guidance from health professionals who work with children and young people in your target audience.
- Keep the information focused on one key area so 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 or more information.

Teaching programme raises awareness of testicular health in boys and young men

A group of healthcare professionals, children, young people and teachers have co-created a teaching programme about testicular health. It aims to raise awareness of the symptoms of testicular torsion among boys and young men.

Led by Barts Health urologist consultant and director of the urology network, James Green, the group has developed a number of **free online resources**.

The resources have been shared with thousands of schools across the UK via **the PSHE Association**.

Over the next two years, the team will be working on a wider roll-out across north-east London boroughs. Healthcare professionals and health information producers are encouraged to **share the resources** with their networks.

Ask target audiences about approach to sensitive topics | Case study | Crohn's & Colitis UK

Crohn's disease and ulcerative colitis are invisible conditions, which can make it hard for children to understand what's going on in their bodies.

Stigma can mean children experience shame and isolation. It was a priority for Crohn's & Colitis UK to inform and empower children.

To find out what 7 to 11-year-olds wanted, the charity did a literature review, held creative workshops with children, families and carers, and interviewed parents and healthcare professionals.

Children had a preference for digital, visually engaging material. There was also demand for a physical resource from healthcare professionals. It was clear the charity should consider family members as a secondary audience.

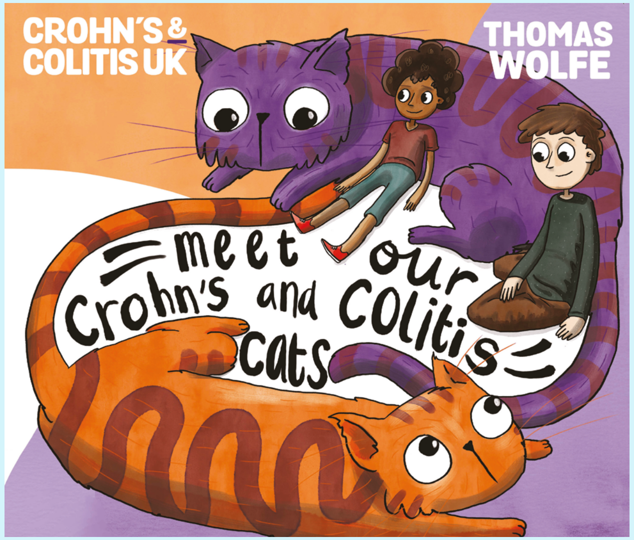
Meet our Crohn's and Colitis Cats is a printed book and an online animation, published in 2020. The charity worked with a children's illustrator and author who lives with Crohn's and is a parent of young children.

It covers difficult and sensitive topics such as having blood in your poo and needing to use the loo frequently.

The charity shared drafts with parents and carers, and asked them to read it with their children. A review form included questions tailored to children, with use of emojis.

The charity also asked healthcare professionals to review drafts.

Feedback led to several changes. These included more about the child's feelings and having a parent with Crohn's or colitis.



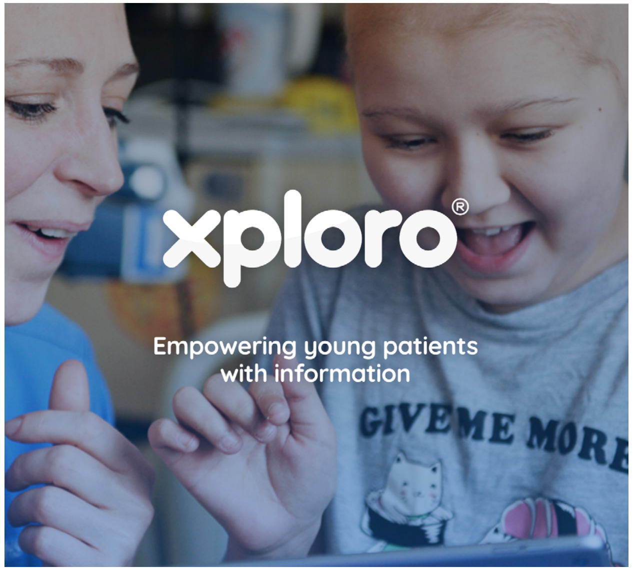
Tip: Even when a resource is based on detailed insights, it is still essential to get feedback on drafts to continue to find ways to improve it.

Visit **crohnsandcolitis.org.uk**

Coping with feelings

Understanding feelings is a vital part of producing health information.

A young person may understand how to manage their diabetes but for social or emotional reasons may not follow the management plan. Children and young people value information about feelings and how to cope with clinical procedures.



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. His young teenage daughter was diagnosed with a rare bone cancer.

The information the family was given was directed at him and his wife, rather than helping his daughter understand what was happening to her. This left 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 platform includes a smartphone app for patients, a web app for parents and a web management portal for healthcare professionals.

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.

An evaluation with 80 children undergoing a range of procedures showed 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.

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

View the platform at **xploro.health**

Pitfalls to avoid

- Making assumptions about children and young people's preferences and abilities without asking them first
- Staff talking to parents instead of to the child or young person
- Using terms children and young people do not understand
- A patronising or disrespectful tone
- Children and young people not being involved in decisions or being given the option to be involved
- Care settings that are unwelcoming or not appropriate.

These difficulties are amplified for children and young people with communication, speech or language differences or those who do not have family support. For instance if they are in care or secure accommodation.

Effective communication is also especially important for young people with long-term conditions moving to adult services. Do not assume they will know everything about their condition.

Tip: Think hard about the tone you use and building rapport with the user. Children like to feel included, encouraged and important.

Parents, families and carers

There is increasing recognition that services should be child-centred rather than family-centred. But the presence and importance of the family and other carers should be acknowledged.

Sometimes it is important to create resources for parents so they feel able to share information with their children. But you cannot assume that all young people will want their families or carers involved.

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 ask questions during consultations. You can see an example of a prompt sheet at **edgehill.ac.uk**

Include ideas or tools for parents to check the accuracy of their child's understanding and identify gaps.

For older age groups, think about providing parallel information resources for young people and their parents and carers.

The information provided to each group must be consistent in terms of facts and key messages.

Make sure you are promoting use of the same language and understanding.

Information for children and young people may also cover conditions that affect other people in the family, such as parents or grandparents.

Many thousands of young people are themselves carers (see page 22).

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. It gives the adult an opportunity to explain and reassure.

Parkinson's UK has updated a series of storybooks, featuring a grandmother, grandfather, mother and father. They are aimed at children aged 3 to 7, to help them understand the condition and how it might affect their family.

The books are available free, 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 familiar with common situations and concerns.
The charity's in-house editors and diversity experts also helped assure quality.

See the storybooks at: 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.

Beyond the family

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

Many health charities now offer young people the chance to share their experiences online, This could be via a moderated forum.

This type of service comes with a lot of responsibility for the provider. Policies and procedures must be in place to handle issues such as safeguarding, data protection and bullying. Key points to consider include:

- What to do if no one answers a post, leaving the young person feeling even more lonely and isolated
- How to ensure that damaging or inaccurate information is not shared
- Whether a forum is purely for support, or could be used for education as well
- If there are ethical challenges, especially in sensitive areas such as eating disorders and other mental health issues.

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

The Teenage Cancer Trust runs **a social network for young people with cancer** called Connect.

The British Heart Foundation runs two peer support groups, **Teen Heart** for teenagers and **One Beat** for young people aged 18–30. Teen Heart was developing its service at the time of writing this guide and not accepting new members. However, it was offering opportunities for young people to be involved in the development.

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.

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

- A child's location to be switched off by default
- Privacy settings to be set to high by default.

Teachers can also help young people find trusted information.
In England, **relationship and sex education, and health education** was introduced into all schools in 2020. In Scotland, health and wellbeing is **part of the national curriculum**. As a result, there are now many health information initiatives in schools.

Independent information-seeking

For most children and young people, the internet, mobile phones and gaming are a part of life.

According to Ofcom:

- Almost 2 in 10 of children aged 3 to 4 in the UK owned smartphones in 2021
- This rose to more than 9 in 10 by age 12 to 15
- 6 in 10 children aged 3 to 4 years old go online, usually via a tablet
- The proportion of children and young people who watch video on demand has increased
- 7 in 10 of the 8 to 15 age group have a social media profile
- TikTok and YouTube are the most popular social media channels for all children and young people.

Information providers are investing in online media for this audience.

It is becoming increasingly clear that **many young people are active and regular users of digital health technologies**.

However, it is also becoming increasingly clear that **digital literacy issues affect young people's use and understanding of digital tools**. Organisations themselves must have expertise in any digital tools and resources they are offering so that they can give support if needed.

The vast amount of information online can be hard to navigate. There is also a lot of misinformation and disinformation.

Social Switch safety project

The Social Switch project offers free training and resources for anyone working with young people who are accessing online resources and social media.

According to **Ofcom**, about 63% of 8 to 15 year-olds are aware that information on the internet may not always be trustworthy. This awareness rises with age. See also page 92.

Children and young people often look to trusted adults to help them make sense of the information they find and to suggest alternative sources.

Apps, artificial intelligence and smart speakers for health

Apps are a fast-growing platform, with more than 100,000 health-related apps now available. Evidence about whether they work and what works best is still unclear.

Providers have a variety of quality standards and checks they can use (see the Expert Self Care case study on page 16).

Smart speakers are also on the rise, with **more than half of homes now owning them**. Channels such as Amazon Alexa and Google Home are also now a possible route for health information.

AI language systems such as ChatGTP and Bard language models have come to the fore during 2023. They can be used to generate extensive and superficially user-friendly 'information'.

There are also **fears AI language systems could fuel the spread of misinformation**. This is a growing and developing area.

AI chatbots and virtual assistants are powered by conversational AI. They can provide instant and accurate responses to frequently asked questions.

They must be carefully set up and regularly updated. Some health information providers have been **using them successfully, both on their websites and on bespoke platforms**.

There are also as yet largely unexplored avenues by the third sector of viral marketing, focused ads, geocoded phone signals or user-induced triggers.

An example might be a young person entering a high-risk area for youth violence receiving ads for knife crime awareness apps.

Free artificial intelligence ethics course online

The OpenWHO online learning platform provides public health courses from World Health Organization (WHO) experts. The courses include **Ethics and governance of artificial intelligence for health**.

Development of mobile health apps and dialogues needs the same evidence-based and user involvement approach as other health information.

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

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Chapter five: Content and design

Key points

- Draw up a plan at the outset.
- The plan must be based on your identified need and target audience.
- Think early about how to achieve regular review, dissemination to a wide range of people in your target audience and evaluation.
- Choose your format carefully. Use assessment of benefits and limitations of each format. Also, ask your target audience what they want.
- Whichever formats you choose, the Golden Rules (see page 64) of writing for children and young people apply. So do the core principles of health and digital literacy.

Getting started

Before starting on any information project, ask these questions:

- Why is this information needed?
- 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?

Answering these questions will establish the need and your audience. You can then move on to making a clear plan for development, delivery and evaluation of your information resource.

The Planning checklist on the next page will help with this.

Remember…

To check the Core20 health inequalities list on page 15

Planning checklist

- ☑ Involving children or young people and safeguarding them
- ☑ Funding development and production
- ☑ Deciding on a budget
- ☑ Identifying the information needs of your audience
- ☑ Involving experts in communicating with children
- ☑ Involving people with expertise in creating health information
- ☑ Ensuring clinical accuracy and relevance
- ☑ Deciding on formats
- ☑ Considering help from creative experts for writing, design, graphics or multimedia
- ☑ Effective dissemination
- ☑ Keeping resources up to date
- ☑ Evaluating the impact and use of the resources.

Golden Rules

Remember to stick to the Golden Rules when writing health information for children and young people. For more details, see Chapter 4, page 64.

Other helpful tips for general accessibility include:

- Use personal pronouns such as 'we' and 'you' to build trust
- Make clear, direct statements
- Do not use complicated punctuation
- CAPITAL LETTERS are harder to read. Words written in lowercase have shape. This helps recognition.
- Italics can be harder to read for people with visual challenges
- Use accessible fonts and sizes
- Use present and active tenses. It is easier to understand 'your appointment is on…' than 'your appointment has been made for…'
- Explain any instructions
- Use everyday words where possible. 'Before' not 'prior to', 'need' not 'require'.
- Avoid use of metaphors.

Reviewing content to stay relevant and up-to-date | Case study | Teenage Cancer Trust

Even though a lot of young people access information digitally, Teenage Cancer Trust made the decision to continue producing its core information book. This was in response to feedback from clinical staff and young people in the 13 to 24 age group.

The resource was also updated to meet five core aims:

- Content review and update
- Design review and update
- Include young people's voices
- Make the guide more interactive
- Incorporate more visual information.

Updates included:

- Changes to reflect the charity's brand refresh including how it speaks to young people.
- Increasing the font size from 9 to 12 pt.
- Illustrations of medical procedures.
- Placing quotes from young people throughout.

To ensure a thorough review, the information was tested in different ways. This included two review groups – one made up of young people who have a personal cancer diagnosis and one of volunteers in the right age group but without a personal cancer diagnosis.

The latter reflected the experience and understanding level of newly diagnosed young people with little or no knowledge of cancer.

Design drafts of the guide were presented at Teenage Cancer Trust's Find Your Sense of Tumour residential weekend. Young people voted on their favourite design styles and said why they had made those choices.

Each section of the guide was also reviewed in detail by at least one member of clinical staff, with 7 different health and social care professionals contributing.

Between publication in January 2023 and March 2023, 1,500 copies of the new resource had been sent out to Teenage Cancer Trust units and other hospitals where the charity funds staff.

View the book at **teenagecancertrust.org**

Tip: Involving users is invaluable. It might sometimes make projects lengthier or feel difficult to do, but it's so important. It means you can complete and deliver a project with the confidence that you've created something that's appropriate, useful and valuable to your target audience.

Choosing your format

Factors that affect your best format decision:

- Your audience and their needs
- 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 format. This will help ensure accessibility and cater for a wider range of learning styles and diverse audiences.

The tables on the following pages look at some of the options and summarise their pros and cons.

Think about including elements specifically to help overcome health and digital literacy barriers. For instance, videos on a website or illustrated panels in a booklet.

Tip: If working with a design agency, allow them creativity but remember they will need your expertise too.

You know your target audience and the type of approach or tone of voice that will work.

'This book is a really good way of explaining Crohn's. I love how the cats shrink and grow when you are feeling bad or good. I also love how they make the feeding tubes fun.

Another thing I love is that at the end it gives you an explanation on all the words that they have used.'

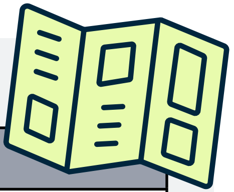
Child user of Crohn's & Colitis UK story book resources for 7 to 11-year-olds (see page 70).

Picture book or story book

Strengths
A familiar and friendly format for children
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 free 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. A leaflet and prompt sheet with links may be more acceptable to some.
Potential accessibility issues for people with low literacy, a first language other than English or visual impairment

Comics

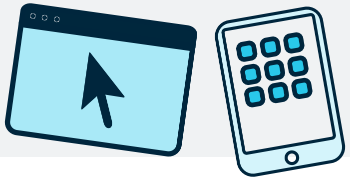
Strengths
Enhance understanding and improve recall
Helpful for people with low literacy levels or whose first language is not English
Can address social or emotional issues through storytelling

Limitations
Inaccessible for people with a visual impairment
Getting the artwork and tone right needs specialist skills
Can be an expensive option

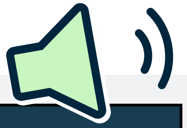
Websites and apps

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
Most young people own a smartphone. Many younger children are allowed to use a parent's smartphone or tablet.

Limitations
Children and young people may find it hard to locate your website, or not consider looking for it. Investment is needed in search engine optimisation.
Not everyone has internet access or can afford to use the data that might be needed. This is 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.
Text may need to be separately adapted for print and screen. People tend to read differently on a screen.
Can be an expensive option



Audio



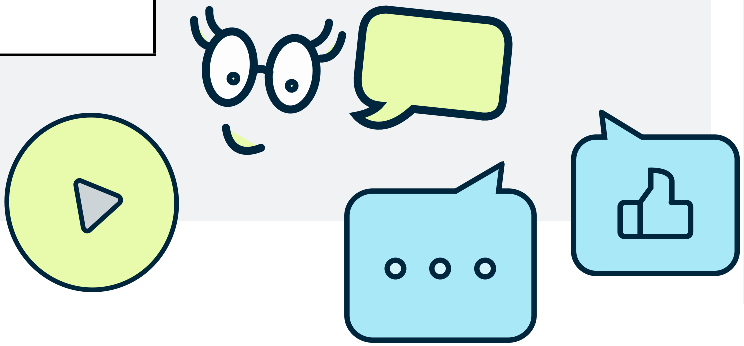
Strengths
Downloads such as audiobooks and podcasts are a familiar formats for most young people
Can be used alone or shared with others
Good accessibility for younger children, people with visual impairment or lower literacy.
Can be recorded in different languages
Can be simple and affordable to produce

Limitations
Some people will not have access to the technology or data needed
No scope for illustrations
Alternatives needed for people with hearing loss.

Video, films and animations

Strengths
Popular format with all age groups, especially via YouTube and TikTok
Effective way to introduce new environments or explain a procedure or process, even to young children or people with low literacy
Can be helpful for people without 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
Need to ensure people with visual impairment or hearing loss are not excluded
Some people may not have access to the technology or data to view
You may need to get more permissions than in other formats. For instance, from people appearing in the background.



Social networking and online communities

Strengths
Very accessible and familiar format for most young people
Can be 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
Needs moderation 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

Research on format confirms the path to success | Case study | MySpira

Asthma is the most common long-term medical condition for children and the most common reason for urgent admissions to hospital in children and young people in England. Yet more than 9 in 10 people with asthma do not use their inhalers correctly.

Correct inhaler use can reduce hospital admissions and deaths from asthma. Studies suggest 3 in 4 hospital admissions and 9 in 10 deaths from asthma are preventable.

MySpira wanted to help children and young teenagers use inhalers effectively and improve their asthma management.

It created an augmented reality asthma inhaler training app for 6 to 13-year-olds. The app includes 8 modules using interaction and gamification.

To check the app represented the most effective approach, the creators commissioned **research by Suffolk University and digital agency Orbital Media**.

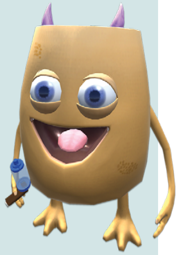
Children were shown both traditional health information about inhaler use and asthma management in several formats, including augmented reality interactive games.

They were asked questions about preferences and how much of the information they could recall from different formats.

The outcome suggested gamification and augmented reality techniques outperform traditional educational methods such as leaflets and videos.

This was particularly noticeable when measuring user enjoyment, learning outcomes and the use of different inhaler methods. It was more noticeable in the 6 to 9 years age group.

At the time of writing, there were plans for an Asthma Control Test to evaluate whether MySpira is improving patient outcomes.



Other developments include web-based resources suitable for use in schools and a version for teenage and adult users.

Visit **myspira.com**

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Chapter six: Evidence and misinformation

Key points

- Ensure clinical accuracy and relevance through research and by involving healthcare professionals and other experts.
- Explain any uncertainties where research findings are not clear.
- Be aware of misinformation and disinformation about your topic. Knowing what is out there, and where, can help you to combat it with trustworthy information.
- New research, resources and courses about tackling misinformation and disinformation are becoming available.

Clinical accuracy and relevance

To aid **in informed decision-making and participation, health information must get its facts right**. This means it must be based on the best, most up-to-date and relevant evidence.

Many children and young people find it hard to work out **whether health information is reliable**. They may call on parents and other trusted adults to help them in this task.

If the information you are offering is based on evidence, it can help people decide whether to trust and use that information.

Often the evidence is not clear because there has not been enough research, or credible research has come up with conflicting results.

If so, do not be tempted to go with one view or the other. It is important to be unbiased and to tell your users about any uncertainty.

There are different **sources of evidence**, as seen in Table 1 on page 89.

Table 1: Different types of evidence

Type	Health information
Clinical research	Information on benefits and risks of treatment
NHS service information	How the NHS should plan your care
Patients, carers, service users, surveys and interviews	What it's like to live with a condition or access health services
Topic experts	Wellbeing and practical information on diet and exercise, for instance
Clinical textbooks, patient groups and NHS patient data	Background on causes of an illness, how many people get it, people most likely to get it and how they respond to treatment

If you regularly produce health information for children and young people on different topics, keep a list of the databases of clinical research you use for literature review. Remember to review this list regularly.

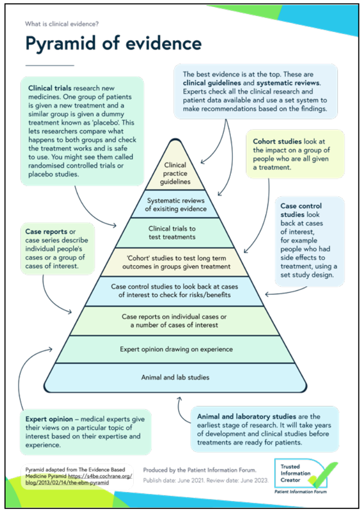
A list such as this does not mean you cannot use other sources where relevant.

If you are not a healthcare professional, you will need to involve healthcare experts. They can be especially helpful in finding and assessing clinical research and other clinical information.

As a non-expert, it can be easy to misunderstand and misinterpret clinical data and practice recommendations.

Even if you are a healthcare professional, it is good practice to involve additional clinical and other experts in the field.

PIF has a number of downloadable posters to help users understand how health information is developed. These include **What is Clinical Evidence?** and **Making Sense of Risks and Benefits**.



What is clinical evidence?

Pyramid of evidence

Clinical trials research new medicines. One group of patients is given a new treatment and a similar group is given a dummy treatment known as 'placebo'. This lets researchers compare what happens to both groups and check the treatment works and is safe to use. You might see them called randomised controlled trials or placebo studies.

The best evidence is at the top. These are **clinical guidelines** and **systematic reviews**. Experts check all the clinical research and patient data available and use a set system to make recommendations based on the findings.

Cohort studies look at the impact on a group of people who are all given a treatment.

Case reports or case series describe individual people's cases or a group of cases of interest.

Case control studies look back at cases of interest, for example people who had side effects to treatment, using a set study design.

Expert opinion – medical experts give their views on a particular topic of interest based on their expertise and experience.

Animal and laboratory studies are the earliest stage of research. It will take years of development and clinical studies before treatments are ready for patients.

Pyramid adapted from The Evidence Based Medicine Pyramid https://s4be.cochrane.org/blog/2013/02/14/the-ebm-pyramid

Produced by the Patient Information Forum.
Publish date: June 2021. Review date: June 2023.

PIF members can also access guidance on **Finding and referencing evidence sources** and **Communicating benefits, risks and uncertainties**.

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.

Hair loss can have a distressing impact at any age. 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.

Penny, a health play specialist, uses role play to help Anna accept what is happening and feel more comfortable about losing her hair. The original author of the book is a hospital play specialist.

Her text was developed by CCLG in consultation with families affected by childhood cancer and healthcare professionals.

There is an online animation version to widen accessibility.

Download the book at **cclg.uk**
View the animation at **youtube.com**

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

Tackling misinformation and disinformation

The spread of health **misinformation and disinformation** – a so-called "infodemic" – became particularly fast and noticeable during the COVID-19 pandemic.

Misinformation and disinformation about COVID-19 related public health measures was seen to be adversely affecting people's take-up of effective strategies.

These included lockdown rules, mask-wearing and vaccines.

The US Surgeon General declared **health misinformation to be a serious threat to public health** in 2021.

However, the size of the effect of **misinformation and disinformation on people's behaviour and health** is not yet well researched.

The World Health Organization (WHO) has produced a toolkit to help combat misinformation and disinformation about health.

You can download a copy of the toolkit from **who.int**. It discusses **public health challenges and health inequality as key topics of misinformation**.

Core misinformation topics include diet and nutrition, alcohol, tobacco and drugs. Misinformation also circulates on topics such as cancer and diabetes treatments. Especially novel and 'miracle' cures.

Making more people aware of how to find reliable health information, and increasing health and digital literacy can help to combat **any effects of factually misleading health messages**.

Free WHO course: Infodemic management 101

There is more information about tackling misinformation and disinformation in the 4 modules of this course from WHO experts.

It is for anyone interested in understanding what an infodemic is, how it dramatically affects public health and what we can do about it, now and into the future.

Visit **openwho.org**

The **PIF TICK** quality standard scheme is featured in the WHO toolkit as an example of a way to flag up trustworthy information to the public.

Look out for the big green tick

The **WHO misinformation toolkit** includes the PIF TICK as a case study for how quality marks can help to stop the spread of misinformation.

Given that social media is a major source of misinformation and disinformation, it also calls on social media companies to work together to tackle misinformation.

In June 2023. the Academy of Medical Royal Colleges **published a new content standard** for health information on social media. PIF collaborated on the development of the standard. The guidance states that organisations accredited by PIF TICK are likely to automatically meet its requirements.

YouTube is also expanding its HealthShelf, which aims to be a source of high-quality, trustworthy video health information.

Both of these initiatives are feeding into an upcoming new PIF TICK quality standard for individuals. Visit **piftick.org.uk**

Trusted Information Creator

Misinformation and opportunity on social media

Superdrug has published a report exploring how people in the UK use social media to find information and advice about their general and sexual health.

A survey of 2,000 UK social media users found 8 in 10 view health and sexual health advice on social media.

The survey also found viewing misleading content can have a negative impact on mental health, general confidence, personal relationships, and social life.

TikTok was named as the most trusted social platform for 16-24-year-olds. It is one of the fastest growing social media platforms, with more than 50 billion views on the #health hashtag and 1.5 billion views on the topic of sexual health.

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, resources specifically designed for young children in collaboration with the children, their parents and carers, and education providers are lacking.

To address this gap, the team developing the Ember the Dragon resources 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.

The resulting animations are underpinned by clinical evidence. The storyboards were designed in collaboration with families.

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: Bring together families and schools to support children and families to feel empowered and supported.

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Chapter seven: Quality improvement

Key points

- Think early about how you are going to reach your target audience. Remember to consider how to widen access to reach all groups.
- Include queries about reaching your target audience in your impact and evaluation plans.
- Have a clear plan of the difference you want to make.
- Make sure your objectives are possible to measure.
- Live service sessions can provide invaluable impact information.
- Make it easy for users to give you meaningful feedback. Let them know what you are going to do with their comments.
- Consider using different feedback mechanisms for children and young people than for parents and carers.
- Have systems and training in place to ensure feedback and impact information are used to improve your resources.
- There are lots of ways to measure impact. Choose the evaluation methods that match your needs, budget and other resources.
- Impact evaluation may show you are not meeting your objectives in the way you hoped. You can use this information to change your approach to be more effective.

Dissemination

Healthcare professionals may have a ready audience in their workplace. Even so, it is worth considering how you might make your information more widely available to children and young people nationwide.

NHS Networks is a web-based platform anyone working in or with the health and care sector can use to share information, network with others and keep up to date with news.

Charities and other third sector organisations can also have a ready audience, for instance via communities of people with the same condition.

You could consider face-to-face outreach work or marketing.

Social media marketing can be an effective and cheap option.

Depending on your budget and audience, channels such as TV, radio and outdoor media are also worth considering.

Think about existing contacts who can help share your resources.

The Dr. Me Project (see page 98) gained publicity by tapping into the contacts of the founder – a clinical leader and award-winning medical educator – and public concern about an overstretched NHS.

It has received national media coverage in **The Times and the Daily Telegraph newspapers**, and on ITV's Good Morning Britain.

Think if there is a related awareness week or day when you could launch your resource.

Consider how people in disadvantaged groups will access your resources.

Local ICSs may be able to help with contact for groups such as young refugees and asylum seekers or gypsy, traveller and Roma communities.

Remember to include in your evaluation plans assessment of how your dissemination strategy is working.

Live impact assessment shows aims being met | Case study | Dr. Me project

The Dr. Me project was inspired by the need to improve health literacy and reduce the strain on the NHS.

It is supported by Health Education England, the Royal College of General Practitioners and the Self Care Forum UK among others.

The project brings volunteer doctors and medical students into primary schools to teach children aged 9 to 11 years.

In 1-hour interactive workshop sessions, children are taught how to self-care for common self-limiting illnesses and when to get medical advice. Another aim is to inspire children to consider healthcare careers, particularly those from disadvantaged backgrounds.

The Dr. Me Project runs on-the-day impact evaluation. A **paper for the Royal College of Physicians** details how six case scenarios were put to 216 children at the beginning and end of the Dr. Me school sessions about:

- Vomiting and diarrhoea
- Sore throat and fever
- Minor and head injuries.

Children decided whether to stay home, visit the GP or go to an emergency department.

Results showed correct responses increased by 16.3% after the sessions.

Feedback forms also showed more than 9 in 10 felt more confident in self-care and more than half were more interested in medicine as a career.

Tip: Have clear aims, which you can evaluate. Results that show you are meeting your aims allow you to move ahead with confidence, widening your impact, reach and credibility. If they show you are not meeting your aims, then you know you need to do something differently.

This shows the project is meeting its aims for health promotion and widening participation to medicine.

It opens opportunities for further evaluation research. This includes reviewing the impact participating in the Dr. Me project has on medical students and their professional development.

Visit **drmeproject.com**

Feedback and impact

It is crucial to understand if your information is making a difference. What is working well and what could be improved? There are many ways to measure this impact, including user feedback.

Feedback from the children and young people using your resources can offer valuable insights when reviewed against your objectives.

It also improves people's trust in you if it is easy for users to get in touch to let you know how they feel about your information.

Tip Welcome all feedback. Children generally love to feel they are helping and can be very honest. Expect to make lots and lots of little changes.

It is worth considering different feedback mechanisms for children and young people than for parents and carers. See the Crohn's and Colitis UK case study on page 70.

When you ask for feedback, you are more likely to get results if you let people know what you plan to do with it and when.

Include a link or reference to your organisation's information feedback policy. This should give details about who will look at feedback, how often, how they will assess it and when new ideas or uncertainties might be incorporated.

To ensure change actually happens as a result of feedback, **it is important to have a system in place for assessing and using it**. People in your organisation should be trained and given the authority to make effective change based on feedback.

Give children a voice that will be heard

Children and young people face barriers when it comes to giving feedback. This can be a particular issue if they are unhappy with a service.

The general principles of a child-friendly complaints service have been **set out by UNICEF**. But there is still a lack of resources of this type.

The Kent Community Health NHS Foundation Trust has created a **set of online user experience surveys for use by children of different age groups**, including an Easy Read version.

Getting better with feedback and evaluation | Case study | IBDrelief

IBDmate is a web-based patient education platform for young people with inflammatory bowel disease (IBD).

After two years in use at Addenbrooke's Hospital Cambridge, the IBD paediatric pharmacist **did a service evaluation**. This found increased knowledge, accessibility, medication adherence and trust in information.

With this evidence and using feedback, outcomes already seen include:

- Patients feeling more confident about their treatments and procedures, with reduced anxiety and a better understanding of their condition. Longer term, it is hoped this will translate to better quality of life for people with IBD.
- Addenbrooke's paediatric IBD team experiencing a reduction in IBD helpline calls and reduced appointment times.
- Anecdotal evidence of people taking the medicines they are prescribed. This could lead to improved disease outcomes.

IBDmate was co-created by **IBDrelief** with the paediatric IBD team at Addenbrooke's Hospital, Cambridge and a group of their patients.

It is now in use at Addenbrooke's, the Royal Alexandra Hospital in Brighton, and Chelsea and Westminster Hospital, London. As well as a large video library, written information and digital tools for people with IBD, their families, carers and friends, there is a healthcare professional (HCP) dashboard. This allows HCPs to set up unique patient records and "prescribe" lessons.

Impact evaluation is a priority for IBDrelief to ensure the platform continues to be relevant and improves to meet new and longer-term aims.

Further evaluation will include a multi-centre paediatric IBD study into the clinical and patient benefits of IBDmate.

Visit **ibdmate.com**

Tip: Spend time getting to know your users. It's the little details of living with a long-term condition that are really important when designing health information. Find out what they do and do not understand, and what would really help them.

To measure impact effectively, you need to have a clear picture from the start of the difference you hope to make:

- What changes you would like to see as a result of children and young people using your health information.
- What you hope the results of such change might be.

Being clear about objectives will help you decide how to measure your progress. This is likely to be through several different methods, including assessing feedback.

You may also have other easily measurable markers, or outputs, to keep track of, such as:

- How many booklets are ordered in a year
- How many page views you have
- How many apps are downloaded.

This type of information in itself will not measure impact.

People may be given or be downloading a resource without using it, for instance. But it can start to build a picture.

Evaluation models such as **Theory of Change**, **Plan, Do, Study, Act** and **Logic Models** may all use this sort of information and include qualitative and quantitative measurements.

Whichever model you use, involve stakeholders inside and outside your organisation. Also, crucially, the children and young people who are using your resources.

Better Evaluation offers free tools to help you identify the best way to measure impact.

Do not feel discouraged if your impact assessment shows you are not achieving the results you hoped for. This is valuable information that will **help you to improve your resources**.

PIF Guide to Evaluating the impact of health information

Extensive guidance on evaluation and practical case studies are provided in the final report of our Perfect Patient Information Journey project.

View the report **here**

Phase 3
The Perfect Patient Information Journey
Evaluating the Impact of Health Information

AbbVie has provided funding support for this report.
Editorial control has remained with the project authors.
Published by the Patient Information Forum 2022.
Updated August 2022 with PIF TICK criteria updates.

Your health information can then join the growing body of work to empower and support children and young people managing their health and wellbeing.

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Chapter eight: Where to learn more

Key points

- Use this section to explore topics from the guide in more detail.

- There are many resources to help you understand the needs of children and young people and produce high-quality results.

- You will find ideas about where to learn more, and source expert support and input for your projects. The links are in the following sections:
- Health policy and need
- Involving children and young people
- Creating health information
- Evidence, dissemination and evaluation
- More inspiring examples.

Health policy and need

Children's Commissioner England
Knowledge and resources hub for parents, carers, teachers, children and young people.
childrenscommissioner.gov.uk

Children's Commissioner for Wales
childcom.org.uk

Children and Young People's Commissioner Scotland sccyp.org.uk

Department of Health & Social Care (England)
For latest policy and guidance. gov.uk

Department of Health (Northern Ireland)
For latest policy and guidance. health-ni.gov.uk

Equality and Human Rights Commission
Learn about your organisation's legal obligations to make health information accessible to all.
equalityhumanrights.com

Friends, Families and Travellers
Charity with more information about the healthcare neds of the gypsy, traveller and Roma communities.
gypsy-traveller.org

Health and Social Care (Scotland)
For latest policy and guidance. gov.scot

King's Fund
All the charity's output on improving health and social care for children and young people in England. kingsfund.org.uk

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ncmd.info

National Institute for Health and Care Excellence (NICE)
All NICE products on children and young people. Includes any guidance, advice and quality standards. nice.org.uk

NHS digital information
NHS Digital merged with NHS England and Health Education England in March 2023.
For more information about services and standards. digital.nhs.uk

NHS England
Sets out the roadmap for personalised care as standard by 2023-24. england.nhs.uk

NHS Knowledge and Library Services
Resources, advice and evidence. Includes a free e-learning course about health literacy. library.nhs.uk

NHS Long term plan
Online version of this 10-year roadmap for development of the NHS. longtermplan.nhs.uk

NHS Youth Forum
Reports and resources by and about young people. byc.org.uk

Public Health Wales
For latest policy and guidance. phw.nhs.wales

Royal College of Physicians
Analysis of the healthcare needs of the traveller community. rcplondon.ac.uk

Social Care Institute for Excellence
Resources and information about children in care and care experienced people. Created in collaboration with 80 young people. scie.org.uk

Young Minds
Information and resources about the needs of child refugee and asylum seekers. youngminds.org.uk

Involving children and young people

Association for Young People's Health
AYPH works to meet the particular health and wellbeing needs of 10-25 year olds. ayph.org.uk

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

NSPCC
Information on safeguarding children and child protection. nspcc.org.uk

Royal College of Paediatrics and Child Health
Resources and guidance on child health, safeguarding, and involvement. rcpch.ac.uk

Royal College of Paediatrics and Child Health
A guide giving information to ensure the safe, meaningful and ethical participation of children and young people. rcpch.ac.uk

Social Care Institute for Excellence
Guide and resources to co-production with young people. scie.org.uk

RNID
Information and guidance on communicating with people who have hearing loss. rnid.org.uk

Young Minds
A suite of participation toolkits with guidance on how to increase involvement of children and young people. youngminds.org.uk

Creating health information

Association of Translation Companies
ATC is the professional membership association for translation companies and sets quality standards and best practice.
ATC.org.uk

BBC Bitesize
Get in touch with education and find a wealth of high-quality resources. bbc.co.uk

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

Department of Education Northern Ireland
Education policy, reports, guidance and the curriculum. education-ni.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

Early Years Learning Alliance
Gain insights into early years education.
eyalliance.org.uk

Equally Ours
Information, resources, training and guidance to ensure your approach is inclusive.
equallyours.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.
fredrogerscenter.org

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

Learning Wales
Education policy, reports, guidance and the curriculum. gov.wales

Orkan O et al, 2018.
Generic health literacy measurement instruments for children and young people: a systematic review of the literature.
bmcpublichealth.biomedcentral.com

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. ciol.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.
healthwriters.com

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

Me First
Tools and advice to support development of knowledge, skills and confidence in health and social care professionals communicating with children and young people. Produced by Common Room Consulting and Great Ormond Street Hospital. mefirst.org.uk

Medical Artists' Association of Great Britain
Find an illustrator for your project. maa.org.uk

Northern Ireland Commissioner for Children and Young People niccy.org

Medical Journalists' Association
Find an expert 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

Evidence, dissemination and evaluation

BetterEvaluation
Help, support and guidance on evaluating health information products. betterevaluation.org

BMJ Best Practice
What is the best evidence and how to find it. bestpractice.bmj.com

Dartmouth College
An A-Z listing of evidence-based medicine resources. dartmouth.edu

Digital Agency Network
Listing UK health marketing agencies with proven track record in health and medical information marketing and dissemination. digitalagencynetwork.com

Gov.uk
Guidance on evaluating digital health products. gov.uk

Health Evidence. A US site helping people find and use the best and most up-to-date evidence. healthevidence.org

New Philanthropy Capital
A consultancy for the charity sector with a focus on impact evaluation. Offers resources online and support. thinknpc.org

NHS Knowledge and Library Services
Resources, advice and evidence. Includes a free e-learning course about health literacy. library.nhs.uk

NHS Networks. A free resource for anyone working in or with the health and care sector to share information and network with others. networks.nhs.uk

Patient website
Information on finding medical evidence. Different levels of evidence. patient.info

Patient Information Forum
Case studies, information and resources. pifonline.org.uk

PMLiVE. List of forty marketing agencies with a UK healthcare focus. pmlive.com

UK Faculty of Public Health
Information about a training module on finding the evidence. healthknowledge.org.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

Further inspiring examples

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

Break
break-charity.org

British Heart Foundation
bhf.org.uk

Crohn's in Childhood Research Association
cicra.org

CLIC Sargent
clicsargent.org.uk

Great Ormond Street Hospital
gosh.nhs.uk

Macmillan Cancer Support (see cancer info for teens and young adults) **macmillan.org.uk**

National Deaf Children's Society
buzz.org.uk

Teenage Cancer Trust
teenagecancertrust.org

Teenage Health Freak
childrenshealthscotland.org

The Strength of my Scars
strengthofmyscars.com

The Teen Sleep Hub
teensleephub.org.uk

Young Minds
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 contact PIF at **info@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**.

Join us

PIF is the independent UK membership body for people working in health information and support. PIF runs the only UK-wide quality mark for health information – the PIF TICK.

PIF represents more than 300 organisations across the NHS, voluntary, academic, freelance and commercial sectors. Our expert guidance on the production of high-quality health information supports an improved healthcare experience for patients and the public.

Our vision

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

Our Partners

abpi
ATC Association of Translation Companies DEFINING STANDARDS OF EXCELLENCE
AstraZeneca
Boehringer Ingelheim
Bupa
CANCER RESEARCH UK
FCB HEALTH EUROPE
Healthcare Information For All HIFA.org
MACMILLAN CANCER SUPPORT
MSD
National Voices
NICE National Institute for Health and Care Excellence
PAGB
Pfizer
PRSB Professional Record Standards Body
texthelp

Published by the Patient Information Forum
483 Green Lanes, London, N13 4BS

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