

## Accessible patient information

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# The need for patient information

Why and how?



#### **Shared decision making**

"Collaborative approach to healthcare decision-making that involves patients and healthcare professionals working together to make decisions that are informed by the best available medical evidence, as well as the patient's values, preferences, and goals"

Accessible health information is key to patient empowerment



#### Fifteen-minute consultation: Empowering children, young people and families through shared decision-making: a practical guide

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Roodwell 11 June (NZ) Accepted 29 February 2004 Published Online (Inc.)

#### ABSTRACT

approach to haulth-use discover-making that involves palents and healthcare professional working together to make elections that are informed by the best available medical existence as well as the publishts values, preferences and with. The inspectance of NDM and the introducinterplay among payents, children and young remake IC VIV. and height-size rentensionals are reveninds advowledged as the trustel aspect of delivering high-quality passificities year. While there, is a substantial entdence have for 5260 Improving Krawledge and Industry decisional coeffet, the evidence for long-term measures such as improved feedth outcome is britised. and matrix reconstance. To topport healthcare teams in implementing SDM, the without offer a practical guide to ordance decision making processes and empower CYF and their fundion

#### BACKGROUND

Shared decision-making (IDM) is an essential, mandated part of buildingre. When done well, it can transform a patient's experience 'Benearch descontains that IDM can reduce decisional conflict and health inequalities, and improve patient showledge and satisfaction (table 2).

For children and young people (CVP), trails outlined in this are it is important to consider issues such as safeguarding, consent, and the role of patents or cries's when including SDM within a care pathway. Developing authorony is a bey component of a page of the Collaborative or a part of the Collaborative as part of the Collaborative as part of the Collaborative and programments of the collaborative and programment of the collaborative as part of the Collaborative and programment of t

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no adult nervices.

5DM is embedded in the National Hasish Service (NHS) constitution for England and key UK consultations such as 'Ne decision about me without ner'. National Institute for Health and Care Excellence (NICE) guidance has also bean published? Globalls, 5DM has been processed by meny organisations including the American Academy of Pediatrics and the Aportalisas Commission on Safety and Quality in Nashbasse.

In the UK, legal coundecensors such as the Montgomery v Lanarkohire Health Board judgement and updated General Medical Council guidance have amphasized the need for paediance healthcare reason to be skilled in practicing SDM and to have access to suitable resources. Despite all of these immatives, CYP and their parents carers are still not always involved artisls has drawn on 2021 NICE. modency, recent literatury including systematic reviews and the authors tools outlined in this article were Japanete developed by the Ready Steady Ge (RSG)-TIER Cellaborative. The authors of this paper actively countrileured to the development of these tools





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### Benefits of shared decision-making

Domain	Explanation
Literature involving children and young people patients	
↑ health outcomes	Better asthma adherence, less complications and less delayed exacerbation. Improved functional disability and reduced school absenteeism in rheumatology
↑ satisfaction	More involved in their care, better understanding of conditions. More satisfied with care.
↑ knowledge	Better understanding, treatment options, and benefits and risks of options
↑ trust ↓ decisional conflict	More collaborative relationship. Where there is uncertainty, reduces anxiety
↑ alignment with patient goals	Helps align care with the patient's goals, values, and preferences.
Literature involving adult patients only	
↓ health inequalities	Benefit disadvantaged groups (e.g. lower literacy) more than higher literacy, education and socioeconomic status, if tailored to disadvantaged groups
Evidence lacking in literature	
Healthcare costs	Choose more conservative approaches when better informed
Medical errors	No data

atients

#### **Accessible health information**

- Systematic review of using patient information leaflets (24 studies)

- 43% of adults' literacy levels < age 7-9 year olds</li>
- NHS websites require reading age ≈ 16 year olds
- 42% UK adults unable to understand typical health leaflet, 61% when numeracy skills required

Sustersic et al. Health Expect (2017) 20(4):531

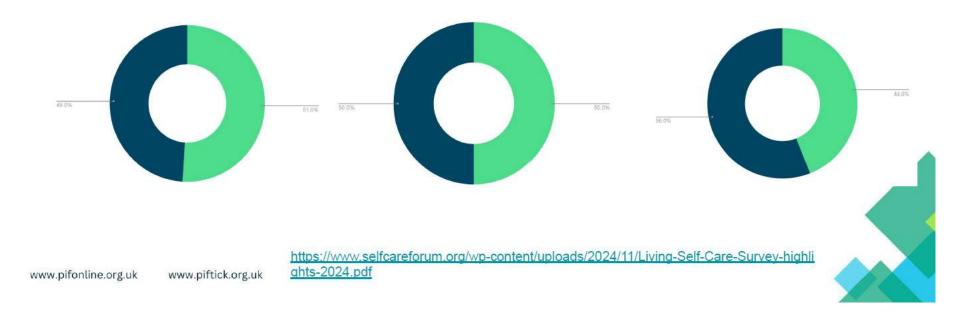




#### What does this mean for health literacy?

5 in 10 people have difficulty judging the advantages and disadvantages of different treatments. 5 in 10 people have difficulty deciding how to protect themselves from illness using information from the mainstream media.

4 in 10 people have difficulty finding information on how to handle mental health problems.







#### Which is better?

5 out of 1,000 will have a complication

Blood will be taken from you by the nurse

Passive voice



0.5% will have a complication

The nurse will take your blood

Active voice







#### Key risk communication guidance from NICE

- Think about using a mixture of numbers and pictures, for example, numerical rates along with pictograms or icon arrays, to allow people to see both positive and negative framing at the same time
- Use numerical data to describe risks if available. Be aware that different people interpret terms such as 'risk', 'rare', 'unusual' and 'common' in different ways
- Use absolute risk rather than relative risk. For example, the risk of an event increases from 1 in 1,000 to 2 in 1,000, rather than the risk of the event doubles
- Use natural frequencies (for example, 10 in 100) rather than percentages
- Be consistent when using data. For example, use the same denominator when comparing risk: 7 in 100 for one risk and 20 in 100 for another, rather than 1 in 14 and 1 in 5
- Present a risk over a defined period of time (months or years) if relevant. For example, if 100 people have treatment for 1 year, 10 will experience a given side effect
- Use both positive and negative framing. For example, treatment will be successful for 97 out of 100 people and it will be unsuccessful for 3 out of 100 people



**W UKKA** 

NG197 (shared decision making) recommendations 1.4.9 to 1.4.11



# Patient Information Committee

**Objectives & output** 

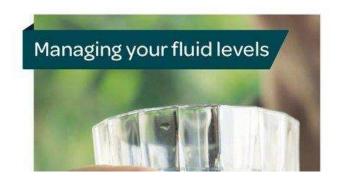


### Strategic objective





#### Conditions, symptoms and living well













57 leaflets completed; 5 more imminent 317,000 hard copy orders 1,499,645 unique website users in 2024







#### Other media, other languages













#### Patients at the heart of our work

- Online focus groups
- Listening to many different groups of patients
- Visiting patients in many units across UK
- Feedback from Patient Support & Advocacy Officers











### **Patient Information Forum**

**PIF TICK accreditation** 



#### **Patient Information Forum (PIF) TICK**

Trusted
Information
Creator

**Patient Information Forum** 

- Replaced NHS England's Information Standard
- Quality mark for print and online patient information
- Robust and standardised production and review processes, with user testing and feedback

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





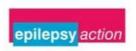


#### Charities and health organisations accredited include...

























































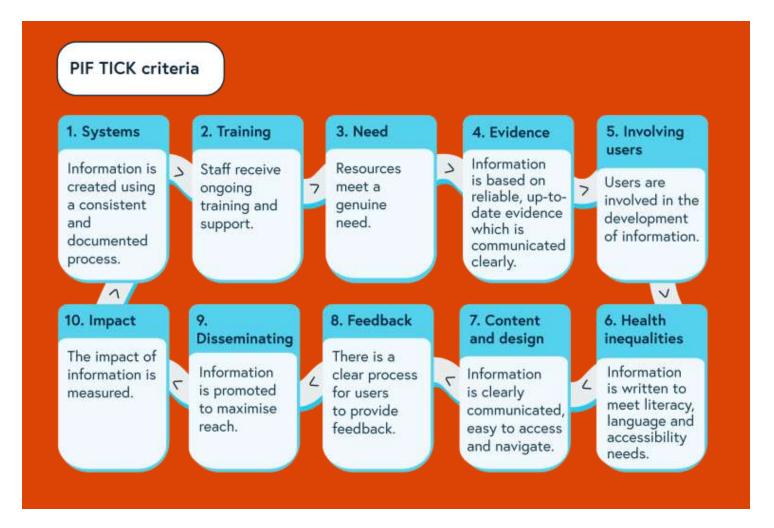








#### Assessment criteria









## **Partnerships**

Widening our information offer



#### **Partnerships**

 Links with other charities and organisations enable us to utilise their specialist expertise:













#### **Co-production example**

Worked with Managing Access by Generating Improvements in Canulation (MAGIC) team to produce How to check your fistula and advice on needling

- Demonstrated patient need for the resource
- Extensive expert clinical input
- Dedicated photoshoot to include images of real patients











#### **Co-production example**



#### https://infokid.org.uk



- Kidney conditions in babies, children and young people
- Written information available as online pages and pdf downloads
- Expanding to include patient stories and animations
- **2024 unique users:** 162,848 and **2024 total page views**: 256,354; 71% via mobile







#### **Kidney Kitchen**















#### **Rare Hub**





Donate

## Rare kidney conditions

Rare kidney conditions affect around 70 in 100,000 people. Nearly all children with endstage CKD have a rare disease. For at least 3 in 5 children and 1 in 9 adults with end-stage kidney disease, kidney failure is due to rare disease.



Find patient information about specific rare kidney conditions

Search through our kidney conditions listings

About kidney disease ∨ Help and support ∨ Get involved ∨ About us ∨ Health professionals ∨





#### Rare Hub

- Building on work conducted by RareRenal and the RDGs
- Information revised and updated
- Complemented with patient story videos, lifestyle pieces and general information on living with a rare kidney condition
- 1,751 unique users so far in 2025



#### Rare renal conditions: an > overview

Whether you or your child have recently been diagnosed with a rare kidney disease, or you've been living with one for a while and want to understand more about it, this article offers an introduction to living with a rare kidney condition – and what you can expect from treatment.



#### Living with a rare condition

Living with any long-term condition can be challenging, but having a rare disease – or being told your child has one – can feel very isolating, and may have a big impact on your emotional wellbeing. But you're not alone, and there are lots of steps you can take to help yourself and your family.



#### Community support for rare kidney conditions

If you are living with a rare condition, building a community around yourself can help you feel less isolated, access the latest information and share your lived experience to give hope to others.

https://kidneycareuk.org/rare-kidney-conditions



