

# 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



# 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  |

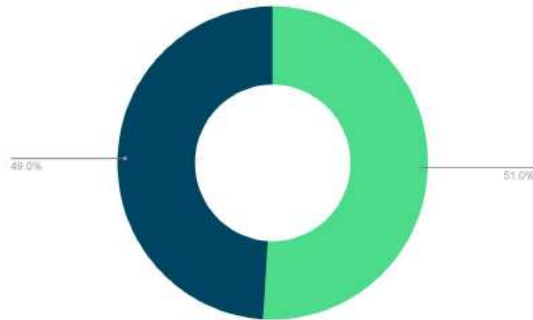
# Accessible health information

- Systematic review of using patient information leaflets (24 studies)
  - All conditions: ↑ patients' knowledge and satisfaction
  - Acute conditions ↑ adherence to treatment, Chronic mixed impact
- 43% of adults' literacy levels < age 7-9 year olds
- 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

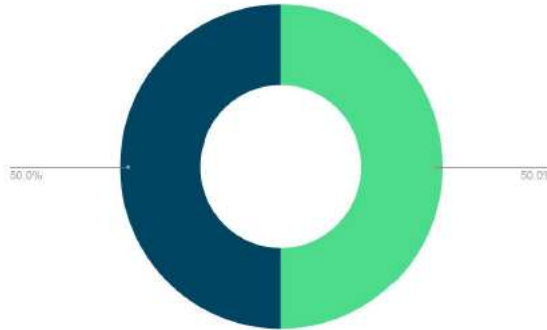
# What does this mean for health literacy?

5 in 10 people have difficulty judging the advantages and disadvantages of different treatments.



[www.pifonline.org.uk](http://www.pifonline.org.uk)

5 in 10 people have difficulty deciding how to protect themselves from illness using information from the mainstream media.



[www.piftick.org.uk](http://www.piftick.org.uk)

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



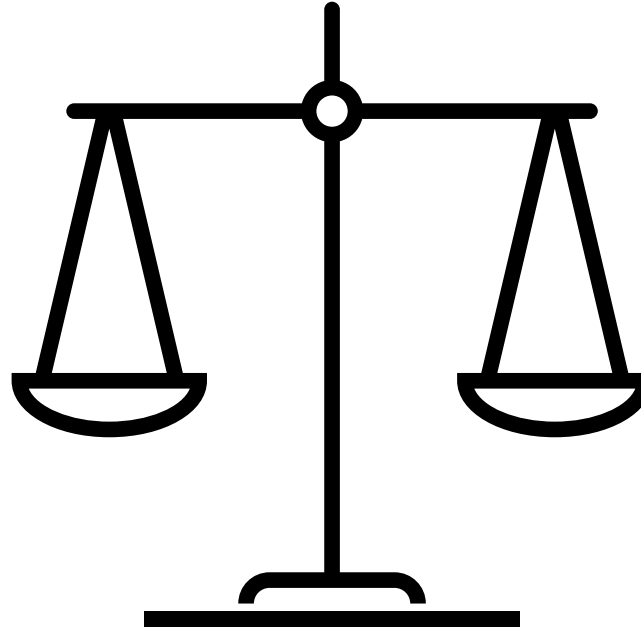
<https://www.selfcareforum.org/wp-content/uploads/2024/11/Living-Self-Care-Survey-highlights-2024.pdf>

# 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

NG197 (shared decision making) recommendations 1.4.9 to 1.4.11



# Patient Information Committee

Objectives & output

# Strategic objective



# Conditions, symptoms and living well

Managing your fluid levels



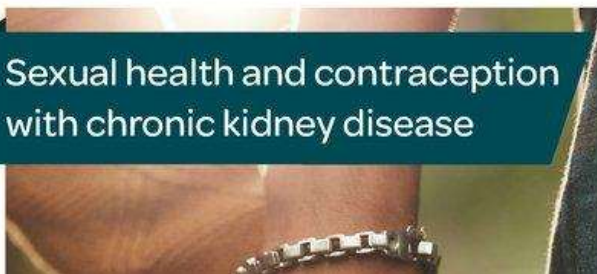
Haemodialysis access with an arteriovenous fistula



Acute Kidney Injury



Sexual health and contraception with chronic kidney disease



Itching and chronic kidney disease (CKD)



An employer's guide to kidney disease



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



- 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...



Improving life for

kidney patients

# Assessment criteria



# Partnerships

Widening our information offer

# Partnerships

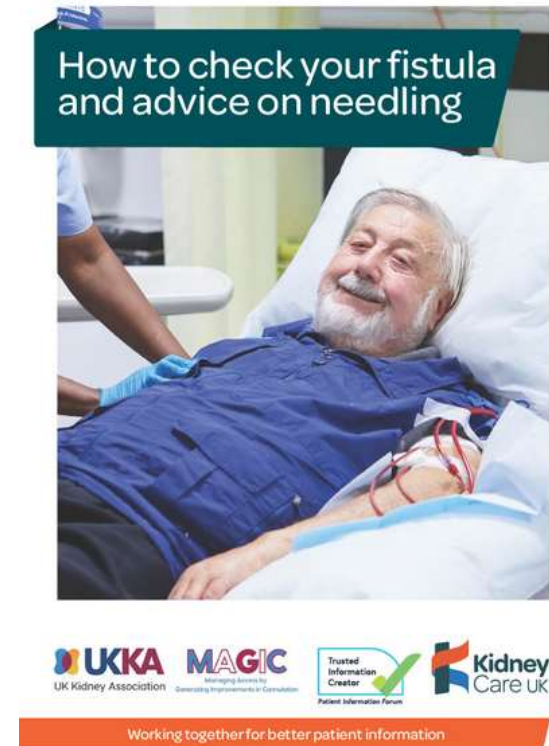
- Links with other charities and organisations enable us to utilise their specialist expertise:



# 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**



Improving life for

kidney patients



# Kidney Kitchen

12 healthy and  
kidney-friendly  
lunch ideas

Kidney Kitchen



Improving life for

kidney patients



# Rare Hub



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## Rare kidney conditions

Rare kidney conditions affect around 70 in 100,000 people. Nearly all children with end-stage 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](#)



Improving life for

kidney patients

# 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>