



**Patient  
Information  
Forum**

# 26 years of healthcare information

Improving access to high-quality, accessible healthcare information was the mission of the Patient Information Forum (PIF) when it was founded 25 years ago. That mission remains the same today.

This timeline shows how information has evolved in the last 25 years. PIF's role in campaigning for and providing guidance on high-quality patient information is as relevant now as it was in 1997.

The independent voice of UK health information  
[pifonline.org.uk](http://pifonline.org.uk)

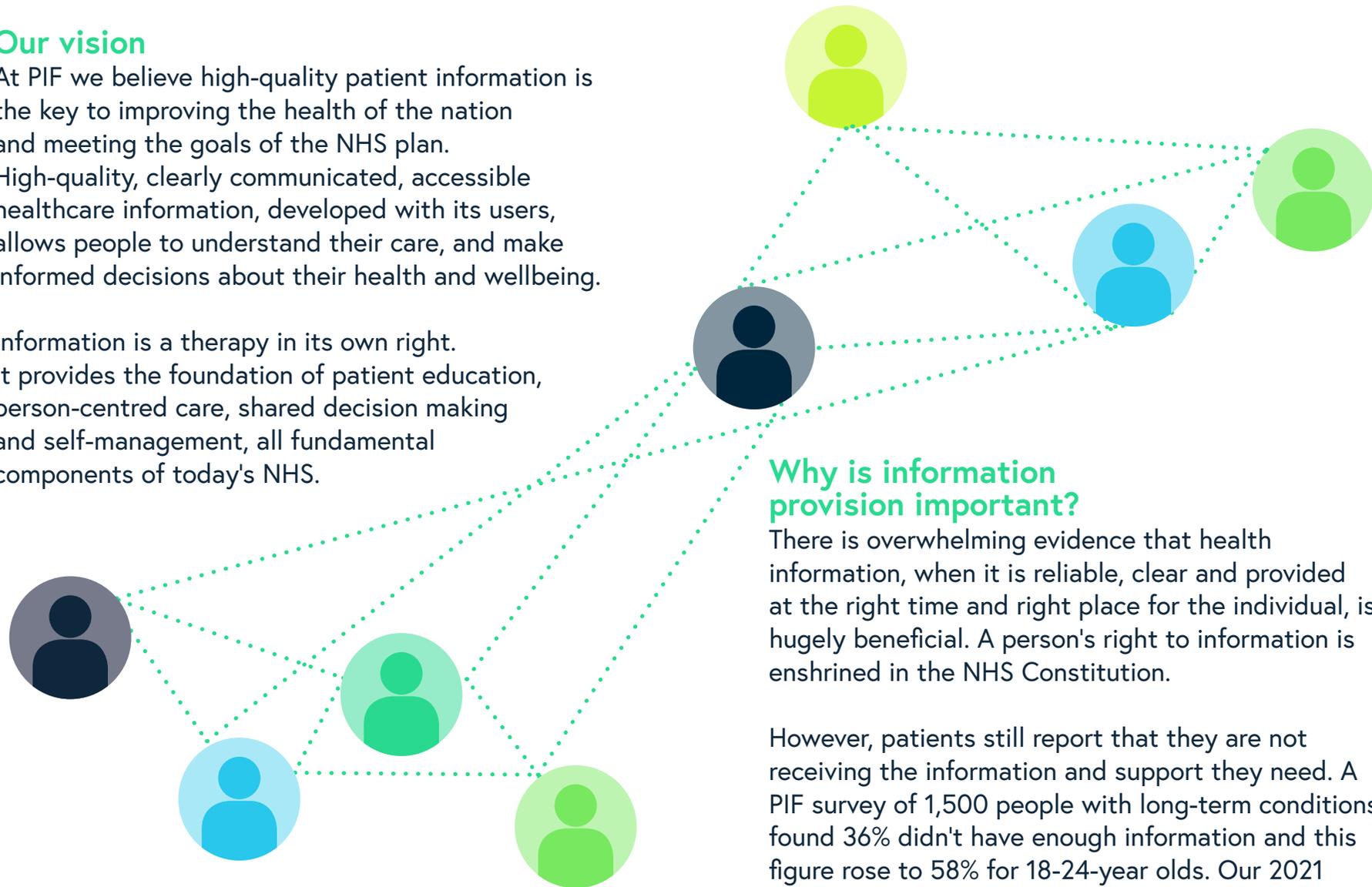
# Introduction

by Sue Farrington, Chair

## Our vision

At PIF we believe high-quality patient information is the key to improving the health of the nation and meeting the goals of the NHS plan. High-quality, clearly communicated, accessible healthcare information, developed with its users, allows people to understand their care, and make informed decisions about their health and wellbeing.

Information is a therapy in its own right. It provides the foundation of patient education, person-centred care, shared decision making and self-management, all fundamental components of today's NHS.



## Why is information provision important?

There is overwhelming evidence that health information, when it is reliable, clear and provided at the right time and right place for the individual, is hugely beneficial. A person's right to information is enshrined in the NHS Constitution.

However, patients still report that they are not receiving the information and support they need. A PIF survey of 1,500 people with long-term conditions, found 36% didn't have enough information and this figure rose to 58% for 18-24-year olds. Our 2021 maternity survey found 50% of women felt they had insufficient information to make an informed choice about induction of labour.

## Empowering patients

If patients are to take greater responsibility, we need to respect their rights and enable them to participate. Information is an intervention that impacts health and wellbeing and it contributes to all three aspects of quality care – clinical effectiveness, safety and patient experience. It improves outcomes and contributes to cost effectiveness.

Healthcare information is not just leaflets, booklets and signage. Today's landscape is much broader; it includes appointment and discharge letters, informed consent, digital personal health records, websites, apps and social media. Importantly, there is a growing recognition of the role of health literacy and the need for the NHS system to change the way it interacts with people.



## Our members

PIF has evolved over the last 25 years. We started life, under the auspices of the King's Fund, as a small group of patient information professionals who wanted to share their work and learn from each other. Today we have members working in more than 300 organisations within the NHS, voluntary, academic, commercial and freelance sectors across the UK. We are proud of our work and are a trusted partner of cross sector organisations.

PIF members provide an invaluable service in enabling patients to feel more informed and in control of their healthcare decisions. The PIF TICK scheme provides a means to demonstrate the commitment members make to providing trusted health information.



## The future

Challenges lie ahead: keeping up-to-date with evolving digital technology, new complex medicines need simple explanation, health information and engagement needs to reach all groups in society.

PIF also has to adapt to meet these challenges. In our anniversary year we applied for charitable status. In 2023 we were registered as a charity by the Charity Commission.

We look forward to working with you our members, to demonstrate the impact high-quality health information has on outcomes, particularly for the most vulnerable. This is our major focus for the coming years.



**Sue Farrington,**  
Chair, Patient Information Forum

## About us

### The Patient Information Forum (PIF)

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

Our work involves: delivering resources and events for information producers and providers; influencing to raise the profile and quality of health information and bringing together those interested in the field of health information and support.

The PIF membership body come from across all sectors, representing every kind of information and support producer and provider, from the NHS to large international companies, health charities to national health departments, researchers to freelance medical writers.

PIF is committed to improving the healthcare experience for patients and the public by helping individuals and organisations to deliver high-quality, evidence-based, accessible information and support so that everyone can understand their care, and make informed decisions about their health and wellbeing choices.



[pifonline.org.uk](https://pifonline.org.uk)



[linkedin.com](https://linkedin.com)



[twitter.com](https://twitter.com)

# 26 YEAR TIMELINE

## EXTERNAL

## INTERNAL

1997

Google search engine launched.

### The New NHS

Marked 'a turning point for the NHS'. Introduced PCTs and initiated the introduction of new services to provide information.

Patient Information Forum (PIF) established under the auspices of the King's Fund by Mark Duman.

PIF's first logo launched.



Patient Information Forum

1998

### NHS Direct and online website

NHS Direct was a nurse-led telephone information service, which provided basic healthcare advice to callers and directed those with more serious complaints to the appropriate part of the wider NHS. The website included health information, online symptom checkers, and access to the online enquiry service. Closed in 2014 and replaced by 111 service.

'Providing health information should be about the patient's agenda. What matters to them?'

1999

### Saving lives. Our healthier nation

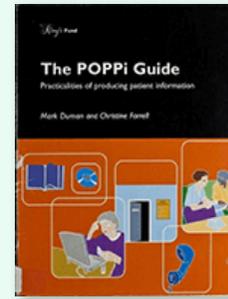
Call for people to 'make their own decisions about their own and their families' health'. Recognised the connection between education status, literacy and health.

2000

**The NHS Plan: A plan for investment, a plan for reform**  
10-year plan for information delivery to be personalised, empowering individuals to take responsibility for their own health 'The NHS will shape its services around the needs and preferences of individual patients, their families and their carers.'

**Our National Health; A plan for action, a plan for change (Scotland)**  
Provides a statement of national priorities for health and for the NHS and highlights 'People want better, clearer information about treatment options at the right time'.

PIF Founder authors **Producing Patient Information – How to research, develop and produce effective information resources.**



2001

Online information hub **Wikipedia** emerged.

'Information provision is not a one stop process. It should be provided at regular points along the care pathway, via channels to suit the accessibility needs of the patient.'

2002

**Securing Our Future Health: Taking a long-term view**  
– **The Wanless Review**

Embedded within this 20-year vision is the concept of providing consumers with appropriate information, being a key requirement to empowering them to take more responsibility for their own health.

**Expert Patients Programme**

Programme to improve self care support and create an expectation that patient expertise is a central component in the delivery of care to people with chronic illness.

'I love the PIF forum and newsletter. It's invaluable.'

PIF MEMBER

2003

**Building on the best: Choice, responsiveness and equity in the NHS**

Stated that the 'NHS will empower patients individually' and 'Ensure people have the right information, at the right time, with the support they need to use it'.

**Copying Letters to Patients: Good Practice Guidelines**

Introduced to support doctors copying letters to patients.

**Informing health care (Wales)**

Set out a vision for transforming healthcare in Wales through the introduction of tools and techniques appropriate to the Information Age.



**LinkedIn** business and employment-oriented social network launched.

'Ensure people have the right information, at the right time, with the support they need to use it.'

BUILDING ON THE BEST: CHOICE, RESPONSIVENESS AND EQUITY IN THE NHS, DEPARTMENT OF HEALTH

2004



**Facebook** social networking website started.

**Liberating the NHS: Greater choice and control**

Sets out plans to give people greater choice and control over their healthcare, supported by a new culture of shared decision making and an information revolution that will give people the information they need to make effective choices.

**Choosing health: Making healthier choices easier**

Introduced three core principles of a new public health approach: Informed Choice, Personalisation and Working Together.

**New GMS (GP) contract**

Contract to incentivise GPs to focus on chronic conditions, provide information to patients and measure patient experience.

**NHS Reform Act (Scotland)**

Duties of patient focus, public involvement and equal opportunities were placed on NHS Boards.

'I continue to enjoy seeing and using the great resource PIF produces. You really are a wonderful organisation.'

PIF MEMBER

2005

- PIF regional workshops held in Oxford and the North East.
- PIF event on **Health Screening Information** held in London.

'This event has been invaluable in forming ideas on how we take the provision of patient information forward.'

PIF MEMBER

**Mental Capacity Act**

Designed to protect and empower people who may lack the mental capacity to make their own decisions about their care and treatment. *'Information is given to enable a person to understand the information relevant to the decision... use or weigh that information as part of the process of making the decision. A person is not to be regarded as unable to understand the information relevant to a decision if he is able to understand an explanation of it given to him in a way that is appropriate to his circumstances (using simple language, visual aids or any other means).'*



Smart phone revolution began.  
**YouTube** free video-hosting website established.

2006

- PIF workshop on the **Book Prescription Scheme** held in Cardiff.
- **First PIF Annual Conference** took place.



**Twitter** online news and social networking service began.

**Our health, our care, our say: a new direction for community services**

Called for radical and sustained shift in the way services are delivered; more personalised to individuals' needs with a focus on facilitating empowerment of people with chronic conditions.

**Patient Focus and Public Involvement (Scotland)**

Highlights patient information as one of its four key themes.

2007

- New PIF logo launched.



**Patient Information Forum**  
communicating for better health  
[www.pifonline.org.uk](http://www.pifonline.org.uk)

- **PIF Annual Conference** held in London.

**NHS Choices website launched**

Provides a health information service to help the public make the best choices about their health and lifestyle, as well as making the most of NHS and social care services in England.

**Better Health, Better Care: Action Plan (Scotland)**

Commitment to putting patients at the centre with a consistent approach to the production of high-quality health information across NHS Scotland and information partnerships with the voluntary sector.

### Health and Social Care Act 2008

Sought to enhance professional regulation and create a new integrated regulator, the Care Quality Commission, for health and adult social care, with focus on providing assurance about the safety and quality of care for patients and service users.

### High Quality Care for All – Darzi Review

Focused on developing local services tailored to *'the needs of the patient within the context of their support network, including carers, family and employers'*. Recognised 60% of people feel they are not getting the support they need from the NHS to take more responsibility for their own health.

## 2008

- PIF incorporated and Directors appointed.
- PIF members **online registration system** goes live.
- Network of **Regional and Country Co-ordinators** created.
- **First skills audit** of the PIF membership took place.
- **'Information as a Therapy'** first discussed at PIF's Networking Event.
- PIF event on **Meeting Diversity in Patient Information** held in London.
- PIF Annual Conference on **Producing Effective Information for Patients** held in Manchester.

### The NHS Constitution for England

Identified health information as a key standard with which NHS Trusts must comply. It established patient information as a right and is supported by legislation (Section 2a). *'The NHS commits to offer you easily accessible, reliable and relevant information to enable you to participate fully in your own healthcare decisions and to support you in making choices'*

### The Information Standard (TIS)

A certification scheme and quality mark for health and social care information producers established.



## 2009

- PIF authored **'The state of consumer health information: an overview'**.
- **PIF job advert service** introduced.
- New **PIF Aware** newsletter design introduced.
- First meetings of the **PIF Advisory and Strategy groups**.
- **PIF Query service** introduced for PIF members to ask for advice and help on specific challenges amongst their peers.
- PIF workshops on **Appraising Health Information and Health Information for Children** held in London.
- PIF Annual Conference on **Producing Effective Information for Patients** held in Manchester.



### **Liberating the NHS: Equity and Excellence**

*'Evidence shows that involving patients in their care and treatment improves their health outcomes, boosts their satisfaction with services received, and increases not just their knowledge and understanding of their health status but also their adherence to a chosen treatment' and 'Information, combined with the right support, is the key to better care, better outcomes and reduced costs.'*

### **Care Quality Commission**

Essential standards of quality and safety published.

Care Quality Commission regulations state that *'service users, or others acting on their behalf, should be provided with appropriate information and support to understand the care or treatment choices available to them'*.

### **Healthy Lives, Healthy People:**

#### **Our strategy for public health in England**

Promises to empower individuals to make healthy choices and have access to personalised services.

#### **Quality 2020 (Northern Ireland)**

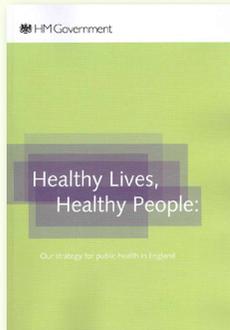
10-year strategy designed to protect and improve quality in health and social care in Northern Ireland.

### **Healthcare Quality Strategy for NHS Scotland**

Key themes include clear communication and explanation about conditions and treatment.

### **NHS Inform (Scotland)**

Scotland's National Health Information Service established.



- PIF takes part in review process of **BMA Patient Information Awards**.
- New **PIF membership** categories and benefits announced.
- PIF/Health Foundation jointly **hosted dinner** on shared decision making took place.
- **PIF Guide to Appraising Health Information** published. This guide is about assessing the quality of information, and the processes used to develop it. This resource has been archived.
- PIF introduces **new Partner membership** category. Macmillan Cancer Support become the first PIF Partners.
- PIF **Member of the Month** slot introduced.
- First **PIF membership survey** undertaken.
- PIF **standards for high-quality information** published.
- Review of PIF's **governance arrangements** undertaken.
- PIF conducts **first survey into patient information provision** in the NHS and finds that *'53% of NHS Trusts believe patient information services within their Trust are under threat or will be cut; 40% do not have a defined budget for patient information provision'*.
- PIF fully engaged in responding to the DH consultations on the **Information Revolution and Greater Choice and Control**, based on members' views and a roundtable discussion with Partners.
- PIF joins **Dept of Health Information Standard Engagement & Development Board and PROMS Stakeholder Reference Group, NHS Inform (Scotland) Advisory Group and NHS Alliance PPI Steering Group**.
- Roundtable dinner held on **Shared Decision Making** with Health Minister, in partnership with The Health Foundation.

### **PIF held events on the following topics:**

- PIF Annual Conference on Patient Information: Moving Beyond Leaflets
- Information Standard and Social Care
- Healthy Journalism
- Learning Disabilities
- Developing an Information Strategy
- Health Literacy and Health Information
- Personal Health Records

### **Liberating the NHS: An Information Revolution**

Provides a summary of responses to the Government's consultation and states '*People should have the information they need to stay healthy, to take decisions about and exercise more control of their care, and to make the right choices for themselves and their families.*'

### **Making Shared Decision Making a Reality –**

#### **No decision about me, without me**

Describes shared decision making as '*a process in which clinicians and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient's informed preferences.*'

#### **Patient Rights Act (Scotland)**

States that healthcare received should '*enable the patient to participate, taking all reasonable steps to ensure that the patient is supplied with information and support in a form that is appropriate to the patient's needs.*'

### **Transforming Your Care: A Review of Health and Social Care (Northern Ireland)**

Overarching road map for change in the provision of health and social care services in Northern Ireland, which led to Health and Social Care On Line.

#### **The Health Foundation MAGIC**

#### **(Making Good Decisions in Collaboration) programme**

Explored how to embed best practice in shared decision making.

2011



PIF joins **Twitter**.

**Ask About Medicines website** information is absorbed into PIF website.

New **PIF logo** launched.



**Patient Information Forum**  
Raising the standard of consumer health information  
[www.pifonline.org.uk](http://www.pifonline.org.uk)

**PIF Regional and Country Co-ordinators** continued to operate in 9 out of 11 areas.

Contributed to the Future Forum report on information, including the ideal **patient information journey**.

**Proud to be a PIF member** badge launched.



**Executive Circle meeting** held with Sir John Oldham – National Clinical Lead, Department of Health.

#### **PIF held events on the following topics:**

- PIF Annual Conference – Meeting the Challenges in Health Information
- PIF Scotland Conference – The Rise of Consumer Health Information
- Health Information in the Digital World
- West Midlands Partnership Event
- Making the Case for Consumer Health Information
- Issues and solutions in producing and providing health information

**Health and Social Care Act**

Provided the most extensive reorganisation of the structure of the National Health Service in England to date.

**The Power of Information: Giving people control of the health and care information they need**

Set out a 10-year framework for transforming information for the NHS, public health and social care. It describes information as *'an essential service in its own right, allowing us to understand our own health, choose healthier lifestyles, and the treatment and support that is right for us'*.

**Liberating the NHS:****No decision about me, without me**

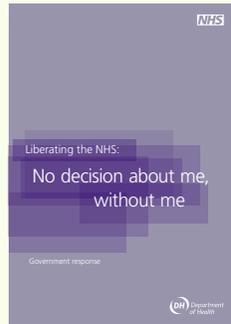
Outlined more detailed proposals to increase opportunities for patients and their representatives to have more involvement in decisions about their care all along the patient pathway.

**A framework for NHS patient experience**

Information is one of the eight areas that the National Quality Board's NHS Patient Framework set out for measuring patient experience in England.

**Together for Health (Wales)**

Set out a 5-year vision for the NHS in Wales.



PIF strategy and core objectives reviewed.

New **PIF website** launched with event booking and purchase facility.

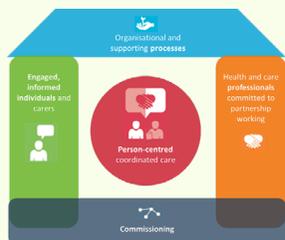
Updated **membership fees and structure** implemented.

PIF / Department of Health Roundtable meeting – **Delivering the Information Strategy** held in London.

**PIF held events on the following topics:**

- PIF Annual Conference - Choice: Valueless without Meaningful Information
- Information Strategy and Consumer Health Information: Implications for the NHS
- Health Information Needs of Diverse Groups
- Evaluating the Impact of Information
- Design in Consumer Health Information
- Differentiating through Exceptional Patient Experience
- Personal Health Records
- Narrowing the Inequalities Gap
- Making Shared Decision Making a Reality

'Information as a therapy.'



First **Fitbit tracker** worn on the wrist.

### House of Care model

Delivering high-quality health information is a vital component within the House of Care Model (the left-hand wall of the 'house').

### Narrative for developing person-centred, co-ordinated care

Department of Health and its arm's-length bodies produced this public commitment to delivering person-centred, co-ordinated care. It can be used by providers, planners and national bodies as the definition of what 'good' integration and co-ordination looks like.

### "Hello my name is..." campaign created

Dr Kate Granger MBE started the campaign in August 2013 after she became frustrated with the number of staff who failed to introduce themselves to her when she was an inpatient with post-operative sepsis.

### Information Prescriptions introduced

Information Prescriptions were issued by healthcare providers to guide people to relevant and reliable sources of information on conditions, services and care.

### NHS 111 service created

The NHS 111 service is staffed 24 hours a day, 7 days a week by a team of fully trained advisers.

### Good Medical Practice – Domain 4, Maintaining Trust – Communicating information – Point 68

Describes what is expected of all doctors registered with the General Medical Council (GMC). *'You must be honest and trustworthy in all your communication with patients and colleagues. This means you must make clear the limits of your knowledge and make reasonable checks to make sure any information you give is accurate.'*

### The Social Care (Self-directed Support) Act (Scotland)

Aims to create a fairer, person-centred social care and support system, with an increased focus on user participation.

2013

PIF elects Board of **Non-Executive Directors**.

First PIF **full-time employee** appointed.

Article authored by PIF **In the know: Raising the profile of patient information.**

PIF authors article **Unlocking the power of information.**

PIF report on survey of **Health Literacy and Health Information Producers** published.

PIF publishes **Guide to Health Records Access.**

PIF publishes **Making the Case for Information** – Brings together the evidence for investing in high-quality information for patients and the public.

New PIF **logo** launched.



**Patient Information Forum**

*For Professionals Working in Consumer Health Information*



Ongoing development of the relationship between PIF and NHS England to **raise the importance of information as part of commissioning high-quality, patient-centred services.**

Task and Finish group took place and generated a series of recommendations for the **development of new Board and staffing.**

### PIF held events on the following topics:

- PIF Annual Conference – Information and support: a service in its own right
- East of England Regional Meeting
- North West Regional Meeting
- Scotland Regional Meeting
- Yorkshire and the Humber Regional Meeting
- Voluntary Sector event
- Long Term Conditions Management
- How patient experience and insight can drive patient action
- The Power of Information Strategy – One Year on
- Personalising information and support for patient and the public

**NHS Five Year Forward View**

Restates a commitment to giving patients choice over where and how they receive care.

**The Care Act**

States that the general duty of a local authority is to promote an individual's well-being '*the importance of the individual participating as fully as possible in decisions... and being provided with the information and support necessary to enable the individual to participate!*

**Personal Health Budgets**

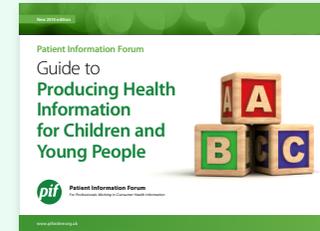
People eligible for NHS healthcare are given the legal right to have a personal health budget. A personal health budget is an amount of money to support a person's health and wellbeing needs, which is planned and agreed between a person and their local NHS team.

**Social Services and Well-being Act (Wales)**

Changed the way people's needs were assessed and the way services are delivered to enable people to have more of a say in the care and support they receive.

**Realistic Medicine – Chief Medical Officer's Annual Report (Scotland)**

Shift from written patient information to use of digital technologies for empowerment of patients.

**PIF publishes Guide to Producing Health Information for Children and Young People.****PIF evidence review published – What does good health information look like?**

This research report summarises the best evidence available on what approaches are most effective in ensuring the accuracy, readability, relevance and impact of health information.

PIF **Sounding Board** established.

Network of **Regional and Country Co-ordinators** absorbed into the PIF Advisory Group.

**PIF held events on the following topics:**

- PIF Annual Conference – Information and support: Putting patients truly at the centre of healthcare
- East of England Regional Event
- Patients as Creators of Health Information
- Developing Accessible Information for Harder to Reach Groups
- Creating Health Information that Works
- Health Literacy
- Shared Decision Making
- Individual participation across the globe

**Richmond Group of Charities 'Vital Signs' report**

Found that 28% of cancer patients were either not given any information or were given written information that wasn't easy to understand. Only 48% of people with schizophrenia had been given information about their medication and only 39% felt it was provided in a way they could understand.

**Local action on health inequalities: Improving health literacy to reduce health inequalities**

Highlighted that '42% of working-age adults (aged 16-65 years) in England are unable to understand or make use of everyday health information, rising to 61% when numeracy skills are also required for comprehension.'

**Montgomery v Lanarkshire Health Board judgment**

The Montgomery case in 2015 was a landmark for informed consent in the UK. This legal judgement defined how risks and benefits should be discussed with patients by healthcare professionals (paragraph 74 onwards).

**Informed health and care –****A digital health and social care strategy (Wales)**

A report published to ensure people make the most of the benefits that digital services can offer to health and social care patients in Wales to ensure 'We are able to access our own information relating to our health and care needs. This will enable us to be in control of our own health and well-being and to play an active role in decisions about the services, care and support we need'.

**Future in mind: Promoting, protecting and improving our children and young people's mental health and wellbeing**

Builds on The United Nations Convention on the Rights of the Child (1992), Article 13, which states specifically that children and young people 'have a right to freedom of expression, which involves being able to find out information for themselves so that they can share it in a way that they want'.

**Digital First Strategy (Northern Ireland)**

Digital First means new or redesigned services must be designed with online services as the primary way for citizens to interact with government.

**PIF Toolkit launched.****PIF publishes Is knowledge Power? report**

This report found that 58% of people find it difficult to access trustworthy information and only 36% feel they have enough information to feel confident in discussing decisions about treatment with their doctor.

**PIF held events on the following topics:**

- PIF 10th Annual Conference – Putting theory into practice: How to empower patients through high-quality health information and support
- Evaluating and Measuring the Impact of Information
- Developing your Business Case for Information
- Meeting the needs of people who produce and provide health information
- Digital Health
- Self-management and Behaviour Change
- Series of events in partnership with NHS England's The Information Standard

**Accessible Information Standard (AIS) introduced**

Introduced to ensure that people with a disability or sensory loss are given information in a way they can understand. It is now the law for NHS and adult social care services to comply with the AIS.

**Patient Activation Measure (PAM)**

PAM is a tool that enables healthcare professionals to understand a patient's activation level – their level of knowledge, skills and confidence to manage their long-term condition.

**Health and Social Care Delivery Plan (Scotland)**

Set out the framework and actions needed to ensure that health and social care services are fit to meet requirements.

**Systems, not Structures – Changing Health and Social Care (Northern Ireland)**

Report of an Expert Panel tasked with producing proposals to deliver safe, high quality and sustainable services for the population of Northern Ireland.

**'42% of working-age adults in England are unable to understand or make use of everyday health information, rising to 61% when numeracy skills are also required for comprehension.'**

IMPROVING HEALTH LITERACY TO REDUCE HEALTH INEQUALITIES  
- PUBLIC HEALTH ENGLAND AND UCL INSTITUTE OF HEALTH EQUITY

PIF launches new **Strategy 2016 - 2021** focusing on four key aims of:

**Quality****Integration****Expertise****Impact**

New **PIF logo** launched.

**Patient Information Forum**

*For everyone involved in health information and support*

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

**Accessible Information online group** launched.

**PIF held events on the following topics:**

- PIF Annual Conference on The Power of Partnership – Working in collaboration to deliver high-quality healthcare information and support
- Communicating Risk in Health Information
- Writing and Designing Health Information
- Integrating Health Information into the Delivery of Care
- Recognising and valuing the expertise of professionals working in health information
- Perfect patient information journeys
- Quality standards in healthcare information and support

**NHS Apps library launched**

Launched as a beta site to provide a library of digital health tools which are accessible to patients, trusted and easy to use and to help them make better choices about digital health and care.

'89% of respondents in our 2017 PIF membership survey said they strongly agreed or agreed that they would recommend PIF membership to a friend.'

**PIF publishes guide to Personal Health Records: Learning from voices of experience**

This guide shares the experiences of people who have first-hand experience of developing or using Personal Health Records.

New **Patient Friend** membership category established.

**PIF Manifesto** published to tie in with general election.

**PIF and our Partners**, MHP Health, publish blog which explores the ongoing quest for a **truly digital NHS**.

Discussions held with the All-Party Parliamentary Health Group and joint event held on topic of **How high-quality information can help patients to better manage their condition: making it part of the patient journey**.

**PIF held events on the following topics:**

- Health Information for Children and Young People
- Improving the Accessibility of Health Information
- Health Information in Scotland
- Personalising Information and Behaviour Change
- Involving Users in Developing Health Information
- Delivering a Patient Information Service – Joint PIF / CILIP Health Libraries Group
- Digital Health Information
- Evaluating and Measuring the Impact of Information
- What evidence is required to enable sustainable investment in health information and support?

**Developing the long term plan for the NHS**

The NHS is working on a plan setting out its ambitions for improvement over the next decade.

**A revolution from within: Transforming health and care (Wales)**

Highlighted '*Strengthen individual and community involvement, through voice and control in health and care, and ensure all ages and communities have equal involvement. The public rightly want a modern service in which they have much better information about health and care, shared decision making in treatment, choice of care and setting, and peer support.*

**A Healthier Wales: our Plan for Health and Social Care (Wales)**

Response to the recommendations laid out in the Final Report of the Parliamentary Review. "*We want to shift services out of hospital to communities... This will include helping people manage their own health, and long term illnesses.*"

**Digital Health and Care Strategy (Scotland)**

Focuses on how digital can support the provision of information, tools and services a person needs in order to help maintain and improve health and wellbeing.

**Review of The Information Standard**

In future, NHS England will focus on embedding the Information Standard as a quality standard, as opposed to certification.

**‘Information, combined with the right support, is the key to better care, better outcomes and reduced costs.’**

LIBERATING THE NHS; EQUITY & EXCELLENCE, DEPARTMENT OF HEALTH

**PIF Perfect Patient Information Journey report and service launched.**

This report was the outcome of a two-year project which explored how healthcare services can develop a Perfect Patient Information Journey.

Podcast recorded with Sue Farrington

– Chair, PIF on **importance of health information.**

PIF and Community Health & Learning Foundation work together to develop a **Health Literate Decision Support Framework** for NHS England.

Refreshed design of **PIF Aware** was launched for its **500th edition.**

**PIF held events on the following topics:**

- Health Literacy and Accessible Digital Health Information
- Health Information Challenges and Solutions
- Communicating Benefits and Risks in Health Information
- Health Information in Northern Ireland
- Digital Health Information
- Perfect Patient Information Journeys
- Shared-Decision Making with the High-Risk Surgical Patient event for Anaesthetists in partnership with Medway Healthcare NHS Trust, held in London
- Communicating Complex Information on Personalised Therapies
- **Measuring and Evaluating the Impact of Health Information**

PIF begins celebrations for its **21st anniversary.**

**NHS App enters the app store**

After testing with more than 3,000 patients across 30 GP practices in England, the NHS App started its public roll out. People can book appointments, manage repeat prescription, check their medical records and check symptoms via the app's health information.

**NHS Long Term Plan Published**

The NHS Plan, published in January, places a focus on national prevention and better care for six priority areas: cancer, diabetes, cardiovascular disease, stroke, respiratory disease, adult mental health; as well as placing a focus on the needs of children and young people and the old.

**NHS X launched**

NHS X, a new joint organisation for digital, data and technology is launched. The unit will take forward digital transformation in the NHS, allowing patients and staff to benefit from the latest digital systems and technology. Digital transformation is a cornerstone of the NHS Plan.

**The Information Standard assessment and certification scheme closes**

The Information Standard kite mark for high-quality health information is discontinued. The former Principles evolve into quality statements, which can be applied voluntarily without an assessment process.



Patient  
Information  
Forum

PIF has a rebrand, including a new logo and new website.

PIF produces the **2019 Health and Digital Literacy Survey**.

PIF announces a **Quality Mark pilot** – a new quality mark to help people identify trustworthy health information.

PIF members represent more than 300 organisations.

**PIF held events on the following topics:**

- Health Information for Children and Young People
- Writing Health Information
- Health Information Challenges and Solutions
- Health Literacy Training
- **Behaviour Change and Health Information**
- **Involving Users in Developing Health Information**
- **Reaching and Engaging with Hard to Reach Groups**

'Improving access to high-quality healthcare information was the purpose of PIF when it was founded in 1997. That purpose remains the same today.'

## 2020

### Marmot Review on life expectancy

The Marmot Review 10 Years On showed life expectancy has failed to increase across the country for the first time in more than 100 years.

### COVID-19 changes the health landscape

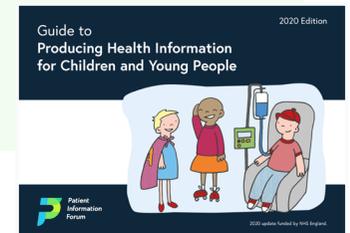
In March, NICE issued its first COVID-19 rapid guidelines and Boris Johnson announced the first UK lockdown. Within the month, the COVID Symptom Tracker was launched. The pandemic highlighted the need for clear, consistent public messaging and culturally sensitive materials.

### Shift to digital health

Lockdown restrictions led to a huge shift to online health information and remote consultations. In March 2020, NHS.uk had more than 61m hits compared to a usual monthly average of 30m. The COVID-19 app launched in September.

- PIF TICK quality mark for health information launched in April after a successful pilot
- PIF responds to the pandemic with the launch of a COVID-19 resources hub
- PIF publishes the Covid Choices survey
- The results of our Health and Digital Literacy Survey are published
- Updated Guide to Producing Health Information for Children and Young People published
- All training is moved online and a series of free webinars is launched to support members

Trusted  
Information  
Creator



### PIF held events on the following topics:

- Writing Health Information
- Using digital tools to maximise health information
- Maintaining the quality of health information in reactive situations
- Risk communication and COVID-19 masterclass
- Remote user engagement
- Health information challenges and solutions
- Round table on health and digital literacy
- What have we learned this year?

Webinar recordings are available to members – log in now and head to the resources section.

2021

### COVID-19 vaccine rollout

The COVID-19 vaccine rollout at the start of the year marked a new challenge for public health information and led to increased awareness of the challenges of misinformation and disinformation. COVID-19 vaccination certificates were added to the NHS app and by December, three years after launch, the app had 22 million users.

### NICE shared-decision-making guideline

In June, PIF member NICE published a new guideline on shared decision making. A shared decision making standards framework was published alongside the guidance to support people using patient decision aids to assess their usefulness and quality.

### Public Health England replaced

In October, Public Health England was replaced by the UK Health Security Agency as part of Government reforms of the public health system.

— Health Literacy Matters poster published

— Co-production Matters poster published

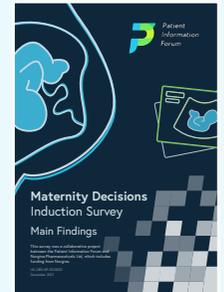
— PIF TICK website launches

— Quick Guide to Web Accessibility published

— Maternity Decisions survey receives more than 2,000 responses and shows there is still much to do to put shared decision making into practice

— PIF joins the Board of the Media and Information Literacy Alliance

— Co-production, Explaining risks and benefits, and Evidence and referencing guides updated



### PIF held events on the following topics:

- Health information challenges and solutions
- Moving forward with health information
- Web accessibility
- Writing Health Information
- Co-production: Involving users
- Health and digital literacy
- Introduction to health literacy
- Using video in health information
- Managing health information translations
- How social media can optimise health information

'Too many of the women who responded to our Maternity Decisions survey felt their concerns and wishes were dismissed. A minority felt bullied and coerced into decisions.'

**Ockenden final report published**

In March, the Ockenden review of almost 1,600 clinical incidents in maternity services at The Shrewsbury and Telford NHS Trust published its final report. It identified failures to listen to families, failure to learn from clinical incidents and failure of multiple external bodies to act in improving maternity services over two decades. Women described feelings of loss of control and power and not being listened to, resulting in psychological trauma.

**WHO publishes excess death figures**

In May, the World Health Organisation published figures suggesting there had been 14.9 million excess deaths associated with COVID-19 in 2020 and 2021.

**PIF held events on the following topics:**

- Health information challenges and solutions
- Inclusive language
- Evaluating the impact of health information
- Writing health information
- The PIF TICK re-evaluation process
- Health and digital literacy
- How and when to review your health information
- Signposting evidence-based health information videos with YouTube and NHS England
- Accessible information
- Evaluating the impact of health information
- Creating Easy Read resources
- Creating an information production process
- Translating health information
- Measuring the impact of health information
- Inclusive language in health information
- Covid information in a 'post-covid' world

PIF partners with the Association of Translation Companies (ATC) to increase access to translated health information across the UK's health sector

The final report of PIF's **Perfect Patient Information Journey** project on evaluating the impact of health information is published

New **Translated Health Information Matters** poster published

PIF joins the Self Care Strategy Group

PIF's three-year strategy is launched with an emphasis on inclusion

A survey of PIF TICK members reveals the impact the robust assessment scheme is having on the production of trusted health information

PIF TICK independent steering group formed

**Quick guide to writing in plain language** published

PIF celebrates 25th anniversary

PIF TICK criteria updated

PIF sat on the project board for PRSB Shared Decision Making guidance

UPD and PIF publish **resources** to help information teams explain data

PIF take part in panel discussion at EBPOW World Congress

PIF featured at PIPA conference

PIF TICK poster **BMI – what you need to know** launched

PIF submits evidence to Government misinformation inquiry

Launch of new CPD-accredited training on editing health information

External events including: Health Literacy UK Conference, Patients Association Partnering with Patients, Digital Services for Patients and Public Symposium

PIF featured in UK Accessible Formats Association webinar

Health and digital literacy survey re-run

PIF TICK highlighted in **WHO misinformation toolkit**

Updated guidance on Translating health information

PIF featured on 'The Frontline' podcast



# 2023

**Primary care recovery plan:** The plan aims to empower people to manage their health via the NHS App, self-referral pathways and greater use of community pharmacy.

**Digital poverty:** More than a million people disconnect from broadband within a year as the cost of the living crisis deepens, say Citizen's Advice.

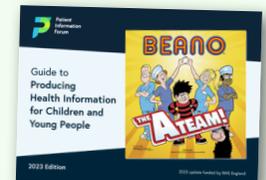
**UK Covid Inquiry opens:** The UK Covid-19 Inquiry opens to examine the UK's response to the Covid-19 pandemic and hear people's stories, with the aim of learning lessons for the future.

**Major Conditions Strategy:** This places a focus on prevention and secondary prevention in six key disease areas: cancers, cardiovascular disease, musculoskeletal disorders (MSK), mental ill health, dementia, and chronic respiratory disease (CRD).

## PIF held events on the following topics:

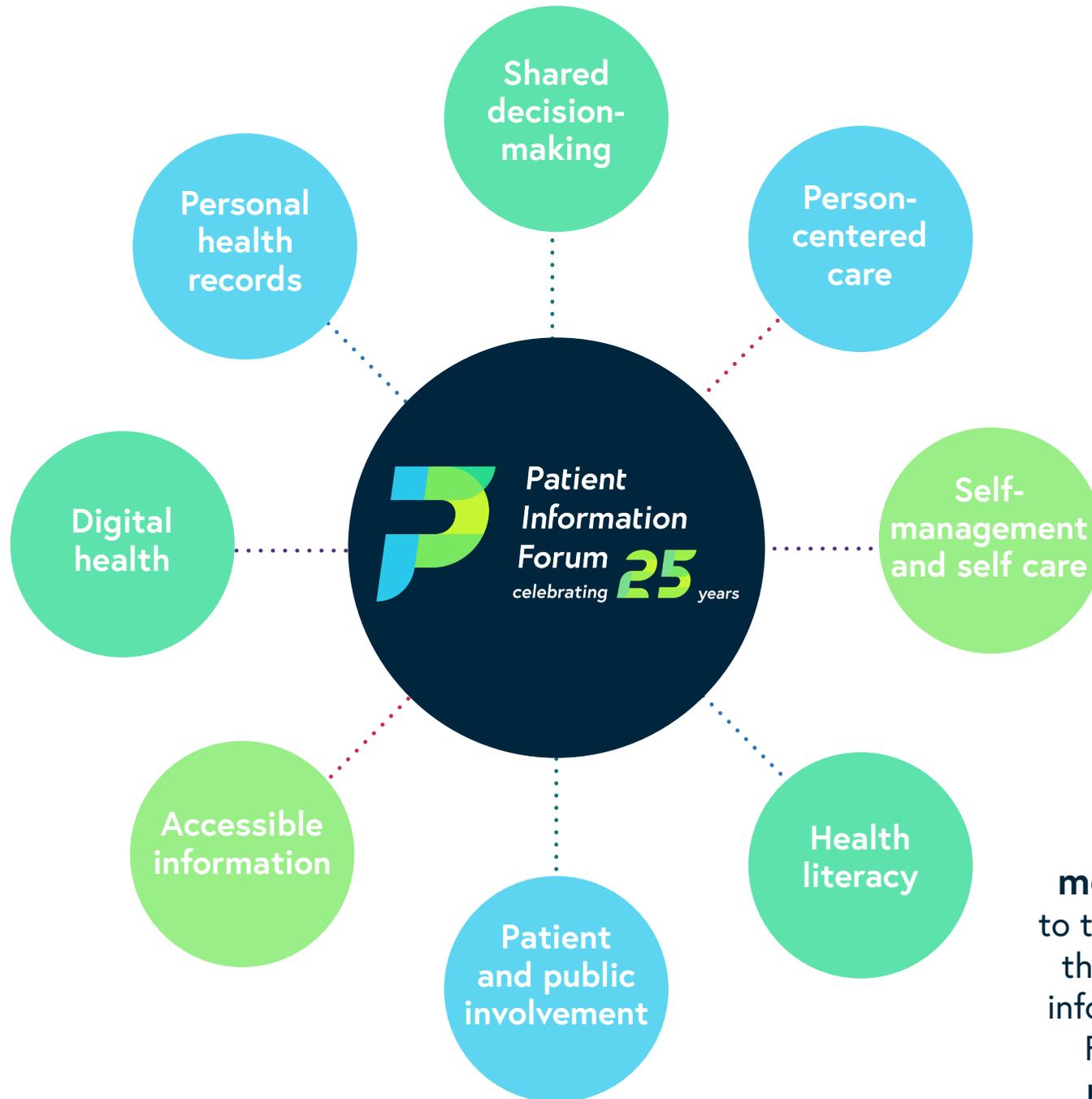
- Health information challenges and solutions
- Shared decision making
- User involvement
- Writing health information training
- Evaluating impact training
- Health inequalities
- Health and digital literacy training
- Working in partnerships on medicines information
- Hybrid event at YouTube on best practices
- YouTube Health Shelf Q&A
- Introduction to content design
- Workshop with Content Design London for charity members
- Producing health information for children and young people
- How to write an information production process
- Web accessibility
- AI in health information
- Bespoke training for Pfizer, AstraZeneca, Nottinghamshire, Boering Ingelheim

- PIF **health and digital literacy survey** results are published
- Launched online assessment portal for PIF TICK
- Launched **member directory for PIF TICK** and ran campaign with Cuttsy&Cuttsy raising awareness with health professionals
- PIF TICK featured in Mail on Sunday column
- PIF attends an ABPI Round Table on data trust
- Collaborated with the Academy of Medical Royal Colleges on a new content standard for social media
- New **Easy Read Matters poster** produced
- Launch of a **Fair Market Value survey** Cancer52 and NRAS and produces a two page report on the findings
- PIF attends Better Medicines Information for Patients Workshop as part of King's College research project
- Joint project with the Patient's Association: **Removing Barriers to Shared Decision Making**
- PIF speaks at the Royal College of Anaesthetists annual conference
- **Health literacy matters poster** is reviewed
- Updated guidance on **Producing Health Information for Children and Young People**
- PIF TICK reaches 100 certified members
- Guide update: **Finding and referencing evidence sources**
- Piloted and launched PIF TICK spot check assessments
- **Web accessibility: a quick guide** is updated



## PIF registered as a charity on 14 July 2023

## High-quality healthcare information is the foundation for:



**Join the PIF membership now** to take part in shaping the future of health information provision. Find out more at [pifonline.org.uk](http://pifonline.org.uk)