

Patient Information Forum



# Review 2024

### Chair's message: A year of change for PIF

PIF became a charity in the summer of 2023. This review covers our first 15 months in this new structure.

Despite the change, our vision remains the same. In fact, it is ever more critical in an era of misinformation, fuelled by the rapid use of generative AI in online search and on social media.



In 2024, we updated the PIF TICK criteria to ensure our standards kept pace with AI and other developments.

In 2023, we opened up PIF TICK certification to health professionals creating content for social media. By the end of 2024, more than 130 organisations and individuals were PIF TICK certified, helping the public find trusted information. We also started work with NHS England to support signposting of PIF TICK health information in public libraries.

Knowledge is Power, published in November 2024, gave a clear view of how people want to access health information and the barriers they face. It revealed inequities in access which compound health inequality and demonstrated the unequal impact of health misinformation. These findings informed our response to the NHS plan consultation, launched by the government.

In 2025, we look forward to working with our growing membership and to ensure everyone has access to credible health information.

Sue Farrington, Chair, PIF

# Our vision

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

# Achievements of the year

PIF started work as a charity on 1 October 2023, since then organisations certified by PIF TICK has grown, as has the PIF membership.

An emerging concern was the use of Al in health information. We issued a position statement on Al in April 2024, with a warning on the use of open generative Al.

The review of the PIF TICK criteria focused on managing the risks and benefits of AI.

12 Training workshops



171

Trainees, plus bespoke in-house training

16 Hot topic webinars and events

1,302 Webinar sign ups



2,950 members

137 certified PIF TICK members To support members we published a detailed framework on policy creation for Al use.

At the end of 2024 we published Knowledge is Power, a state of the nation report on access to health information.

# New posters and guidance

- Health literacy checklist
- Working with medical reviewers guide
- Framework for the use of Al in health information

# Updated guides and posters

- Communicating benefits risks and uncertainties
- Using plain language in health information
- Accessibility matters
- Inclusive language matters
- Translating health information
- Translated health information matters

# 4 Reports

- Al position statement
- Fair Market Value report with a coalition of charities
- Joint report with PRSB on the use of digital portals
- Knowledge is Power



8 Corporate partners

New TICK posters

- Finding trusted health information on social media
- Al and health information
- 1 website refresh
- 1 PIF TICK criteria update

# Our strategic aims 2022-2024

# Quality

PIF raises standards in quality health information and certifies trusted health information producers.

# Integration

PIF campaigns for quality health information and support to be an integral part of the patient journey.

# Inclusion

PIF advocates for health information to be available to all, meeting health and digital literacy, accessibility and cultural needs.

# **Expertise**

PIF enhances the expertise of people working in the field of health information.

# Infrastructure

PIF strives to develop and maintain a sustainable, expanding and financially secure organisation.

### Progress in 2024

The PIF TICK criteria are seen as the definitive standards for trusted health information in an evolving technological landscape.

### Progress in 2024

Knowledge is Power demonstrates the need for health information to be integrated into the patient journey and makes concrete recommendations for change.

### Progress in 2024

PIF's guidance and project work continues to raise awareness of how health information can help tackle health inequalities.

### Progress in 2024

Members are actively engaged in PIF's expertise activities. CPD accredited training, a hot topic webinar series and professional guidance support the achievement of the PIF TICK criteria.

### Progress in 2024

PIF begins operating as a charitable incorporated organisation (CIO).

# Quality – the PIF TICK

The PIF TICK continued to grow in 2023 and 2024 with more than 130 certified trusted information creators. A major review of the PIF TICK criteria responded to the rapid deployment of artificial intelligence tools and growing recognition of the need for translated health information. The review led to the introduction of PIF TICK V3 in November 2024. After a successful pilot, we opened PIF TICK certification to individual content creators. In September, we relaunched our main website, making it easier to access our best practice guidance and showcasing the importance of PIF TICK certification.

### Working with libraries

In October, NHS England included the PIF TICK website in its Health Literacy Toolkit for public libraries. The toolkit supports librarians to connect the public with trusted health information. We also relaunched the PIF YouTube channel. The

we also relaunched the PIF YouTube channel. The channel hosts new videos to help people spot misinformation and signposts certified PIF TICK creators.

#### Trusted health content

In September 2023, YouTube opened its UK Health Shelf of trusted sources of information.

We worked with the Academy of Medical Royal Colleges to define the standards for the Health Shelf. The AOMRC endorsed the PIF TICK in the published content standard.

### Criteria at a glance

- 1. Systems
- 2. Training
- 3. Need
- 4. Evidence
- 5. Involving users
- 6. Health inequalities
- 7. Transparency and legal
- 8. Feedback
- 9. Disseminating
- 10. Impact

### PIF TICK Steering group



Sion Baldwin-Jones Health Content Lead, Parkinsons UK



**Tom Bishop**Head of Patient Information,
Anthony Nolan



**Selina Corkery** Service Manager (Editorial), Macmillan Cancer Support



Caroline DeBrun Knowledge and Evidence Specialist – South West, UK Health Security Agency



Sophie Dopierala-Bull Education and Health Communications Director, CoppaFeel!



Elena Fabbrani
Patient and Public
Involvement Manager, Royal
College of Anaesthetists



Imogen Pinnell
Information and Support
Content Manager, Marie
Curie



Emma Rushton Information and Services Manager, Multiple System Atrophy Trust



Julie Smith Content Director, EIDO Healthcare



**Dr Knut Schroeder**GP and Health Information
App Producer, Founder and
Director of Expert Self Care
Ltd



**Dr Alice Wood** GP and Clinical Director

# Integration

We commissioned Ipsos to carry out research on health information access across the UK. The resulting report, Knowledge is Power, was published in November. It revealed half of UK adults are struggling to find health information they can trust and there are clear inequalities in access to information.

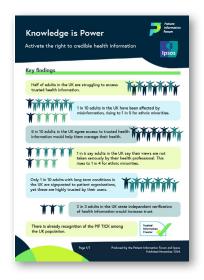
### **Key findings**

- 1 in 5 people with a life-long condition had not received any information from the NHS since diagnosis.
- 1 in 10 people had been impacted by health misinformation, rising to 1 in 5 for ethnic minorities.
- 2 in 3 support verification of health information.
- 1 in 10 young adults are aware of PIF TICK.

#### Recommendations

- 1. Providing health information as a core part of patient care.
- 2. Tackling misinformation through robust standards and effective signposting.
- 3. Making health information accessible and appropriate for all.
- 4. Embedding patient experience as a measure of NHS performance.
- Mandating effective delivery of health information with a named lead in NHS organisations.

Knowledge is Power, and feedback from member consultation, formed the backbone of our response to the 10-year plan consultation. We advocated for better signposting of PIF TICK certified sources of information from NHS services and digital products.



# Signposting trusted health information

The PIF TICK website and PDF directory helps healthcare professionals signpost trusted health information and the public find credible sources. The website is updated monthly and the PDF directory is published twice a year, in March and September.

The website also includes helpful advice on how to find trusted information and spot misinformation. Two new posters were added in 2024 – Finding trusted health information on social media and Al and health information.





# Inclusion

Our work in 2024 continued to support our strategic aim on inclusion. Early in the year we were commissioned by the Sussex Maternity System to co-produce new health information to tackle inequity in maternal outcomes.

We worked closely with local community and voluntary sector groups to identify the information needs of women from diverse backgrounds and communities. Engagement activities helped shape not just the content but also the tone and style of resources.

#### Translated resources

The result was the production of five new easy read resources and accompanying short YouTube videos on maternity care. We also produced a timeline of key points in the maternity journey. These resources were translated into 10 languages.

We again worked closely with community groups to ensure the information reached those that needed it most. The resources are signposted on the maternity system website and on its YouTube channel.



### Fair Market Value

In September, as part of a coalition of charities, we published a guide to fair payment for partnership work. The guidance, Fair Market Value for Charities in Partnership Work, is based on an extensive consultation with charities and funders.

It is designed to help charities and partners calculate FMV and support patient and public involvement activity.



### Health Inequalities Week

In July 2024, we ran our first Health Inequalities Week. Events covered the role of information in tackling inequalities in maternity and cancer care, health literacy and digital inclusion, and disability language in content design.

# **Expertise**

### October 2023

### **Training**

- Health and digital literacy
- **Editing training**

### Webinar

Engaging with seldom heard groups

### Guidance

Co-production guide update

### Bespoke training Astra Zeneca

External events **Shared Decision Making** project presented at CPOC advisory group



### November 2023

### Training

- Writing health information
- · Assessing the impact of health information

### Webinar



January 2024

Webinar Behaviour change and health information

### February 2024

### Webinar

Top tips to streamline your information production process

### December 2023

### Guidance

Communicating benefits, risks and uncertainties update

Health literacy checklist

March 2024

Training

Writing health information

Webinar

Launch of the individual PIF TICK

PIF TICK directory update published

Launch of joint survey with PRSB on patient portals

April 2024

### Training

Content Design London workshop using traumainformed principles in your work

In-person workshop

Member's challenges and
solutions

### Webinar

- Updates from the Ipsos knowledge panel
- Data visualisation

Al position statement

May 2024

Webinar

Digital health and NHS Apps

Guidance

Using plain language update

Accessibility matters poster update

Bespoke training developed for ABPI staff

### External events:

- PIF partners The King's Fund Health Inequalities Conference
- Reading Well for Dementia list launch – PIF on advisory group

Guidance

Working with medical reviewers

Bespoke training CRUK



June 2024

### **Training**

Assessing the impact of health information

First freelance roundtable hosted by PIF

Bespoke training for Ipsen and South Tyneside and Sunderland NHS Foundation Trust

**July 2024** 

# PIF hosts Health Inequalities Week

- Webinar: Health inequalities and health information
- Webinar: How the PIF TICK is improving health information
- Masterclass: Health literacy with Prof Gill Rowlands
- Inclusive language matters poster updated

### Training

Content Design London workshop, disability, language and design

External events

CILIP conference

August 2024

Launch of Knowledge Empowers survey

### September 2024

### Training

- Writing health information
- Content Design London: Creating content in multiple languages

PIF signs open letter to new health minister Wes Streeting outlining the health issues facing the UK.

PIF Directory update



#### October 2024

### **Training**

Creating health and digital literacy friendly resources

Fair Market Value report published

Framework for the use of AI in health information published

Joint report with PRSB on the use of digital portals

#### **Webinars**

- Al and the PIF TICK criteria update
- IPSOS: Is oncology care in the UK equitable?

### External events

- YouTube health creators event
- BluePrint Medicines event for European rare disease charities
- Astra Zeneca lunch and learn

### November 2024

# Training **Editing health information**

#### **Webinars**

- Translating health information
- Knowledge is Power



### Guidance

Translating health information guide update

Knowledge is Power report published

### External events

- EIDO Medico Legal conference
- Royal Society of Medicine's Food and Health Section
- ABPI Strategic Partnerships board

December 2024

### Training

Effective facilitation skills

Response to NHS 10-year plan submitted

Knowledge is Power summary of key findings and recommendations

# Change in status

PIF began operating as a charitable incorporated organisation (CIO) on 1 October 2023. This report covers the activity for the final quarter of 2023 and 2024.

The change from a not-for-profit company to a CIO helps us to operate more sustainably and offers the potential for new sources of funding.

PIF's income in the final quarter of 2023 and 2024 came from four main sources





In 2023 and 2024 PIF received support from the following corporate organisations:



















I would highly recommend using the PIF Ask the Membership service. I had great, really quick responses from members.

PIF member

### Our services support our members

### Strategic Co production

The Perfect Patient Information Journey is our validated process for co-producing health information. It has been used in different sectors and a range of medical conditions.

### Resource review

The PIF Sounding Board is a sensechecking and peer-review service for health information for patients and the public.

### Bespoke training

PIF delivers CPD certified training in a range of formats to meet the exact needs of organisations.

<u>Ask the Membership</u> allows PIF members to tap into the expertise of peers.

# Infrastructure and governance

#### Our team



Sophie Randall Director



Dan Wills PIF TICK Manager



Sheena Campbell Communications Manager



Eugene Thomas Website Manager and Designer



Klair Bird PIF Admin



Claire Utting PIF TICK Assessor



Susan Smith PIF TICK Assessor



Marie Clegg PIF TICK Assessor

### Our board

# PIF is governed by a board of non-executive directors



Sue Farrington Chair



Anne Ballard Non-Executive Director



Graham Parker Non-Executive Director



Jacquie White Non-Executive Director

### Advisory group

### PIF is guided by an advisory group of members

### Kate Betteridge

Neil Betteridge Associates

### Trishna Bharadia

Owner, The Spark Global

### Selina Corkery

Macmillan Cancer Support

### Linda Cowie

FCB Health Europe

### Michele Crooks

Public Health Agency, Northern Ireland

### Joanna Dundon

NHS Wales Informatics

Service

#### **Morag Evans**

Library and Knowledge Specialist

#### Katrina Glaister

Salisbury NHS Foundation Trust

### Lynsey Hawker

The King's Fund

#### **Louise Jones**

Senior Health Information Writer and Researcher, Anthony Nolan

### Steph Jury

Guy's and St Thomas' NHS Foundation Trust

#### Rachael Middle

Isle of Wight NHS Trust

#### Dr Knut Schroeder

**Expert Self Care Ltd** 

### Dr Juhi Tandon

Cognitant Group

### Dr Alice Wood

GP and Clinical Director

# Join us

The Patient Information Forum (PIF) is the membership body for people working in health information and support. We are the independent voice of UK health information. PIF runs the only quality mark for print and digital health information – the PIF TICK.

PIF has promoted access to trusted health information for patients, carers, the public and healthcare professionals for more than 25 years. Extending our influence and impact is only possible with the support of our members and the partnerships we build with likeminded organisations. Find out about PIF membership.

> I think your organisation is brilliant and you are doing a great job. You really care about what you do.

> > PIF member

### Our Partners































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