



Patient
Information
Forum
celebrating **25** years



Annual Review

2022

A message from the Chair, Sue Farrington



Dear members

This Annual Review comes at the end of our 25th anniversary year. Our celebrations have given us an opportunity to reflect on how the health information landscape has evolved throughout PIF's history and the role we have played, as a community, to drive these changes.

A key focus this year has been on our new strategic aim of inclusion. This began with an update to our PIF TICK criteria to place greater emphasis on inclusion and health inequalities. The update was led by a new PIF TICK steering group whose expertise is helping shape the continuing evolution of the UK's only quality mark for print and online health information. This year also saw increasing recognition of the PIF TICK with the World Health Organization featuring it as a case study in its misinformation toolkit.

In keeping with our renewed focus on inclusion, we released new guidance in 2022 to help make sure everyone has access to health information they can understand and use. We published a Quick Guide to Writing in Plain Language and a Guide to Translating Health Information. These were supported by one-page posters on inclusion, accessibility and translation. And we also published a major new report on evaluating the impact of health information.

Throughout 2022 we also worked with the Patients Association, the Nottingham and Nottinghamshire Integrated Care Board and people with lived experience to co-produce shared decision-making resources.

We would like to thank all our members for your continued support over our 25th anniversary year.

Sue Farrington, Chair

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 celebrated our 25th anniversary in 2022, publishing a refreshed strategy with a new strategic aim of 'inclusion'.

We started our anniversary celebrations by updating the PIF TICK criteria, placing a greater emphasis on inclusion and tackling health inequalities. This was supported by the launch of posters on topics including inclusive language, Easy Read and accessibility.

2022 also saw us partner with the Association of Translation Companies (ATC), join the Media and Information Literacy Alliance and rerun our Health and Digital Literacy Survey.

We also published a major new report on evaluating the impact of health information and guidance on translating health information and using plain language.

10 Training workshops

105 Trainees plus bespoke in-house training

13 Hot topic webinars and events

702 Attendees



2 Surveys

- Health and digital literacy
- PIF TICK survey for healthcare professionals

5 posters added to the 'Health information matters' series

- Coproduction matters
- 5 ways to improve induction information
- Inclusive language matters
- Translated health information matters
- Accessibility matters

2 New how-to guides

- Translating health information
- Using plain language in health information



2,234 members

85 certified PIF TICK members



17 Corporate partners



2,258 LinkedIn connections



387.1K Twitter impressions

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.

Quality – the PIF TICK

PIF TICK Steering group

An independent PIF TICK steering group was formed in 2022 as part of our commitment to ensuring the criteria keep pace with a fast-changing health environment.

The group helped to inform our criteria update, which saw a greater emphasis placed on inclusion and changes to reflect the huge evolution in health information since the scheme launched in 2020.

There was increasing recognition of the PIF TICK in 2022 with 85 organisations signed up by the end of the year. A survey of members published in March found 100% would recommend the scheme and 95% had made changes to their information production process since signing up.

WHO Toolkit

A World Health Organization toolkit on tackling misinformation in non-communicable diseases identified credibility marks as part of the solution to misinformation and featured the PIF TICK as a case study.

The TRIP database, Healthnote and HCI video all now use the PIF TICK to verify trusted health information.

The team also supported NHS England with the development of a new self-assessment content standard based on the PIF TICK criteria.

2022 also saw us run a survey, in partnership with Cuttsy+Cuttsy, to identify information needs among healthcare professionals and how we could raise awareness of the PIF TICK.

Steering group



Sion Baldwin-Jones
Health Content Manager,
Parkinsons UK



Dr Belinda Coker
Founder and Medical
Director, YourTrustedSquad



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



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



Emma Rushton
Information and Services
Manager, MSA Trust



Julie Smith
Content Director,
EIDO Healthcare



Emma Wallis
Senior Content Manager,
Diabetes UK



Criteria at a glance

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

Integration

Throughout 2022, PIF and The Patients Association collaborated on a shared decision making project in the Nottingham and Nottinghamshire Integrated Care Board area.

Over the course of six co-production meetings, we worked with the My Life Choices lived experience panel, healthcare professionals and the personalised care team.

The aim was to develop resources to support shared decision making for people experiencing joint pain (musculoskeletal conditions).

Practical tools

The project included reviewing shared decision-making materials and co-producing new materials to be embedded within the Notts NHS App and Patient Knows Best, as well as in non-digital formats. It also looked at the implementation of shared decision-making tools and how and when they are used by patients and healthcare professionals through the shared decision making process.

Patients were asked to share their views on what they want from shared decision-making conversations to help inform a series of recommendations to be published in 2023.

AbbVie has provided funding to support this project, however, control remains with PIF and the Patients Association, who are responsible for overall planning and delivery. No company will have any influence on the outcomes of this project.



SRUK Perfect Patient Information Journey Phase 2

In 2022 PIF continued working with Scleroderma & Raynaud's UK (SRUK) on a Perfect Patient Information Journey for Scleroderma, using the PPIJ methodology tested in our pilot project with St Mark's IBD Service.

Phase 1 of the project, completed in 2021, involved consultation with people with scleroderma and healthcare professionals to identify key information points and any gaps which need to be addressed.

Phase 2 began in 2022 and brought people with scleroderma and healthcare professionals together to identify priorities for change and to develop and test information solutions.

Scleroderma is a rare condition. Rather than targeting one centre and testing the impact of new information we worked with a number of clinical leaders and patients to improve signposting to existing SRUK resources and develop proposals for new projects to plug any gaps identified.

Inclusion

Much of our work in 2022 aimed to support our new strategic aim of inclusion.

In May we launched our Quick Guide to Writing in Plain Language. The guide offers top tips, tools and data to help users make the case for health-literacy friendly materials.

It includes tips on word economy, use of active language, readability tools, talking about risks and benefits and useful links.

Supported by our new partnership with the Association of Translation Companies, we also held webinars and an expert roundtable to help tackle the challenge of providing culturally-sensitive and appropriate translated health information.

We published two resources to support this work – a Translated health information matters poster in February and a Quick Guide to Translation in June, which was updated and expanded in December.

Patient Information Forum

Inclusive language matters

Creating health information everyone can use is about more than plain language. It is about making sure the language and tone you use is appropriate for your target audience. This might be due to:

- Cultural background
- Ethnicity
- Gender
- Disability

Remember one size does not fit all! To reach seldom heard and diverse audiences we need to adapt.

Top tips

- Ask questions
- Write for your target audience
- Read content created by those you want to reach
- Look for conflicting views
- Be inclusive without reducing to stereotypes
- Remember health literacy
- Explain when challenged and adjust when appropriate

Involving users

The best way to make sure your information is inclusive and culturally appropriate is co-production and user testing.

Person-first v disability-first language

- **Person-first** language is the medical model – 'a person with a disability'.
- **Disability-first** language is from the social model – 'I am a disabled person'.

User testing can help you identify the most appropriate model.

Positive not negative

- ✔ 'people have'
- ✗ 'people suffer with'

Try to avoid phrases with negative connotations – 'going down a blind alley' 'tone deaf'

Ask 'why?'

- Why are we using these words?
- What images do we use?
- What colours?
- What tone and branding?
- What assumptions are we making?

Case study: Letting the user choose their terms

CoppaFeel! gives users the option to choose the language most appropriate to them.

self-checkout.coppafeel.org/onboarding-welcome

Produced by the Patient Information Forum. Published June 2022. Review date June 2024.

Trusted Information Creator

pifonline.org.uk

View the full poster series
pifonline.org.uk/resources/posters

Inclusive language

One size does not fit all when it comes to health information.

That is why, to continue our 25th anniversary celebrations in June, we launched an 'Inclusive language matters' poster.

Designed to be a quick reference to help people get started with using inclusive language in their information resources, it covers involving users, person-first versus disability-first language, questions to ask and a case study.

The poster also features top tips from our webinar with topic experts.

Expertise

January

- Partnership with Association of Translation Companies (ATC)
- PIF joins the Media and Information Literacy Alliance

March

PIF TICK webinar
The reassessment process

Survey
100% of PIF TICK members would recommend the scheme



Training

- Health and digital literacy
- Writing health information

May

Webinar
Signposting evidence-based health information video with YouTube

Bespoke training
Delivered to ABPI staff

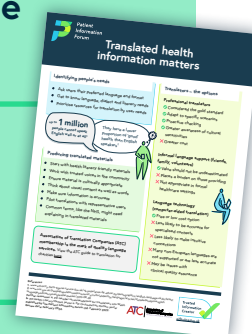
How to guide
Writing in plain language

February

Webinar and report
Evaluating the impact of health information

Webinar
Using inclusive language in health information

Poster
Health information translation matters



PIF joins Self Care Strategy Group

April

PIF TICK webinar
How and when to review information resources

PIF TICK featured at
LILAC Conference 2022

June

PIF 25th anniversary

PIF TICK criteria update

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



July

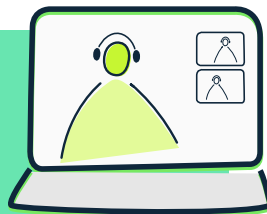
Health Information Week

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

We take part in panel discussion at EBPOW World Congress

September

PIF featured at PIPA conference



PIF TICK poster – Explaining BMI

PIF submits evidence to Government misinformation inquiry

November

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

August

PIF featured in UK Accessible Formats Association webinar

October

Health Literacy Month

Survey
Health and digital literacy

Webinars

- Working with medical reviewers
- Creating Easy Read and image-led health information

PIF TICK highlighted in WHO misinformation toolkit



December

Updated guidance
Translating health information

PIF featured on 'The Frontline' podcast

Webinar
Measuring the impact of health information

Funding

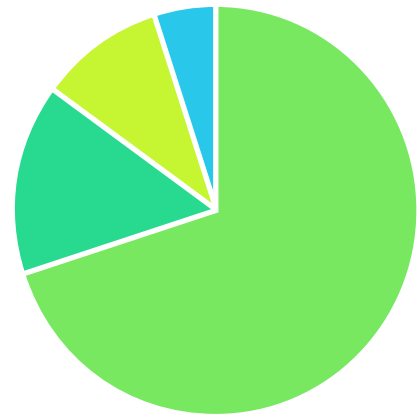
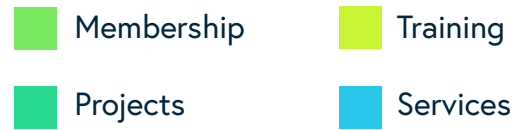
PIF is a not-for-profit organisation.

We rely on four main income streams to generate a small surplus to support the development of member services.

In the last two years PIF's membership has doubled, a result of an expanded range of member services. This has created a more sustainable income base for the organisation.

Our arrangements are transparent and comply with the Good Practice Guidance produced by the Association of the British Pharmaceutical Industry (abpi.org.uk/partnerships/working-with-patient-organisations/working-with-patients-and-patient-organisations-2022-sourcebook-for-industry).

Where our money comes from



In 2022 PIF received support from the following corporate organisations



Our services support our members

Projects, events and services are delivered on a not-for-profit basis.

The **PIF Sounding Board** is a sense-checking and peer-review service for organisations producing health information for patients and the public.

Ask the Membership allows PIF members to tap into the expertise and experience of colleagues and peers. It saves time and prevents reinventing the wheel.

Recruit through PIF allows you direct access to our highly skilled and motivated membership.

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

PIF member

Infrastructure and governance

Our team



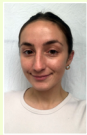
Sophie Randall
Director



Dan Wills
Quality Mark
Manager



Sheena Campbell
Communications
Manager



Arabella Serrels
Website
Manager /
Designer

New staff members in 2022



Charlotte Brownsword
Member
Engagement
Officer



Susan Smith
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

Tom Bishop
Anthony Nolan

Selina Corkery
Macmillan Cancer Support

Linda Cowie
FCB Health

Joanna Dundon
NHS Wales Informatics
Service

Jaina Engineer
Alzheimer's Research UK

Hannah Ensor
Hypermobility Syndromes
Association

Sarah Hennessy
CILIP Health Libraries Group

Katrina Glaister
Salisbury NHS Foundation
Trust

Rachael Middle
Isle of Wight NHS Trust

Dr Knut Schroeder
Expert Self Care Ltd

Dr Juhi Tandon
Cognitant Group

New members in 2022



Lynsey Hawker
The King's
Fund

Join us

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 members come from national charities, the NHS, commercial, government, freelance and academic sectors. Together with them, we produce evidence-based solutions to today's health information challenges. We use the insight and support of our membership to lobby governments in support of our vision.

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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