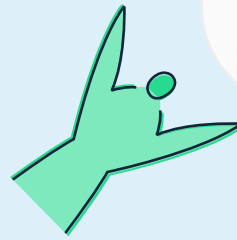
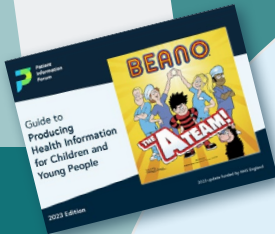




Patient
Information
Forum



Annual

Review

2023

Chair's message: A year of change for PIF



In 2023 PIF marked a significant milestone in our history as the Charity Commission registered PIF as a Charitable Incorporated Organisation. Being awarded charity status was the culmination of a year of work by the team and trustees to submit a successful application.

Our new charitable objects align to our vision that "Everyone has access to personalised health information and support to enable them to make informed decisions about their health, wellbeing and care."

The objects focus our activity on public benefit via supportive member services. The change in status is a mark of PIF's maturity and allows us to build a more sustainable organisation. It also provides the potential to access new sources of funding. The existing PIF Board have become the Trustees of the new organisation to ensure a smooth transition.

This annual review provides an overview of the work done prior to us officially operating as a charity from 1 October, 2023. It has been another hugely busy year with increased recognition of the PIF TICK, major guidance updates and an exciting events programme all helping support our strategic objectives.

Thank you to all our fantastic members and partners for helping to make our successes possible.

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

In July 2023 PIF was awarded charitable status. We started operating from the new organisation on 1 October. Our new charitable objectives align to our existing vision and allow us to continue setting high standards for health information.

This includes expanding the PIF TICK scheme. In 2023 we published the first PIF TICK Member Directory and achieved a significant milestone as Terrence Higgins Trust became

the 100th accredited member.

Meanwhile, an update to our Guide to Producing Health Information for Children and Young People places health inequality and the need to engage children and young people of all backgrounds at its centre.

9 Training workshops

208 Trainees plus bespoke in-house training

14 Hot topic webinars and events

1,312 Webinar sign ups



2,822 members

110 certified PIF TICK members



16 Corporate partners



4 Guidance and poster reviews

- Health Literacy Matters
- Producing Health information for Children and Young People
- Finding and Referencing Evidence Sources
- Web Accessibility

6 PIF TICK poster reviews

- What is evidence?
- Finding trusted health information
- What is clinical evidence?
- False health information
- Making sense of risks and benefits
- What is patient data?

3 Reports

- Health and Digital Literacy Survey Results
- Fair Market Value Survey Results
- Shared Decision Making

1 New Poster

- Easy Read Matters

Our strategic aims 2022-2024

Quality

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

Progress in 2023

The PIF TICK criteria are seen as the definitive standards for trusted health information by members and the wider health economy.

Integration

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

Progress in 2023

PIF's Perfect Patient Information Journey is a validated process for co-production. It ensures information is provided as 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.

Progress in 2023

PIF's Health and Digital Literacy Survey 2023 noted a rise in organisations with health literacy strategies in place. 8 in 10 looked at the equalities impact of digital tools.

Expertise

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

Progress in 2023

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

Infrastructure

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

Progress in 2023

Membership has trebled since 2019. In 2023 PIF was awarded charitable status.

Quality – the PIF TICK

The PIF TICK continued to grow in terms of influence, members and awareness.

The Academy of Medical Royal Colleges (AoMRC) completed its new standards for assuring the credibility of health information sources on social media. The standards were aligned with the PIF TICK and endorsed by PIF. The AoMRC said any organisation meeting the PIF TICK criteria could "easily and perhaps automatically" meet its requirements.

In June, the PIF TICK marked another exciting milestone as Terrence Higgins Trust became the 100th accredited Trusted Information Creator.

Behind the scenes, the launch of a new online assessment portal made it easier for members to manage assessment documentation.

The PIF TICK team also ran two pilots in 2023. The first was to introduce information assessments and the second to allow individual health content creators to join the PIF TICK scheme. Both of these will be fully rolled out in 2024.

Raising awareness

In February we launched the first PIF TICK Member Directory.

The directory was developed after a survey of healthcare professionals found almost 6 in 10 had difficulty sourcing reliable health information to share with patients. It includes all accredited PIF TICK members, and is updated every 6 months.



PIF TICK Steering group



Sion Baldwin-Jones
Health Content Lead,
Parkinson's 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

PIF and the Patients Association worked with NHS Nottingham and Nottinghamshire Integrated Care Board (ICB) to look at ways of making it easier for patients to take part in shared decision-making.

Together we delivered a co-production programme with the My Life Choices panel of local people and the NHS Nottingham and Nottinghamshire personalised care team.

We developed and implemented patient information to support people with hip, knee, and joint pain to make treatment decisions and get fitter for surgery.

A report, developed with input from My Life Choices, outlined our key findings and recommendations. It also shared the co-produced resources developed by the project.

Key recommendations included:

- A national campaign to support patients to know 'It's OK to ask' questions about treatment.
- Adding 'About me' information to the NHS App, linked to the shared care record. This will let healthcare professionals know at a glance what matters most to an individual patient.
- National co-produced resources to be added to My Planned Care to help people waiting for surgery to understand their choices. This should be provided in plain language and accessible formats.

AbbVie provided funding support for this project.



SRUK Perfect Patient Information Journey Phase 2

PIF continued to work with SRUK on the development of a Perfect Patient Information Journey for scleroderma.

We held co-production workshops with healthcare professionals and patients, who worked together to develop materials to meet the information priorities identified.

A poster series to help people find SRUK was developed. An interactive digital journey signposts information from SRUK to support people with a lifelong condition as information needs change.

We also developed an appointment planner to help people make the most of the limited time they have with their specialists. It prepares people to take part in shared decision making.

Images of people living with scleroderma were used on all materials.



Inclusion

Our work in 2023 supported our strategic aim on inclusion. This included a major update to our Guide to Producing Health Information for Children and Young People.

The new guide placed health inequality and the need to engage children and young people of all backgrounds at its core.

It focuses on the practical aspects of creating good health information, choosing the right format, writing for children and tackling sensitive issues.

Fair Market Value Survey

In April we published the results of our Fair Market Value (FMV) survey.

The survey was carried out in collaboration with Cancer52 and NRAS. It found a perception in patient organisations that FMV rates are inconsistent and sometimes less than fair.

Key concerns raised by patient organisations included:

- Low payments meaning they cannot invest time in recruiting from more diverse patient populations.
- The need to cover full expenses for patients and carers.

The results of the survey will be used to produce guidance in 2024. The aim is to help charities charge for their expertise and express their own value when working with industry, research organisations and other stakeholders.

The guide covers stories and play, social media and apps and how to give information.

It provides guidance on digital, mental health needs and working with children who are traumatised or at risk of violence.

Easy Read Matters

We also published a new poster in our Health Information Matters poster series. Easy Read Matters includes top tips to help health information creators start producing Easy Read resources.

Easy Read makes information easier to understand. It can help you meet the Accessible Information Standard. It is also useful for:

- People with English as a second language
- Those who are stressed or time poor
- People with communication difficulties

Top tip: Always test with users to ensure the words and images used convey the message.

Why Easy Read is important

- 1.5 million people in the UK have learning disabilities
- 4 in 10 adults cannot understand health information
- Poor understanding is linked to reduced life expectancy

Top tip: Use nouns instead of pronouns. The doctor will phone your brother, not 'They will phone him'.

Making Easy Read resources

Layout

- Use a logical order – introduction, content, contact details
- Easy Read normally follows the layout shown to the left
- Keep images to the left of the page and text to the right
- Use white backgrounds
- Use a plain 'Sans Serif' font in 14pt or more

Language

- Plain language – check for jargon using a readability tool
- Short simple sentences – 15 words maximum
- Use active voice
- Avoid abbreviations

Images

- Use high resolution images with each sentence
- Capture the main idea of the sentence
- Be representative of users
- Avoid busy backgrounds

Trusted Information Creator
pifonline.org.uk

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

Expertise

January

Member Challenges and Solution Workshop

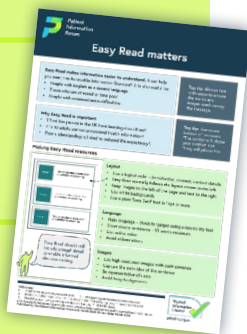
PIF joins AoMRC advisory group on social media content standard

March

Health and Digital Literacy Survey results published

Easy Read Matters poster published

Webinar Addressing health inequalities



April

Webinar Working in partnership on medicines information

Breaking Down Barriers to Shared Decision-Making report published

External events CPOC conference

February

PIF TICK Member Directory launched

PIF TICK webinar Online assessment system

Webinar User involvement

Training: Writing Health Information



May

Hybrid event: YouTube Health Best Practice

Training: Writing Health Information

External events: RCOA conference

Bespoke training developed for ABPI staff

June

Training: Editing Health Information

Webinar
Introduction to Content Design

Training: Assessing the Impact of Health Information

Updated Health Literacy Matters poster published



Bespoke training delivered to Pfizer staff

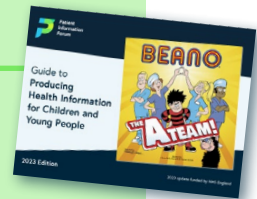
External events including:

- NHS Confed Expo
- Gene People Partnership webinar
- OneVision.Health webinar

July

Updated Health Information for Children and Young People guide published

Health Information Week



August

Finding and Referencing Evidence Sources guide update published

Second PIF TICK directory published

September

Workshop
Health Information Challenges and Solutions

Web Accessibility guidance updated

Bespoke training delivered to AstraZeneca staff

October

On 1st October 2023 PIF moved all of its activity to the new charity and began operating officially as a charitable incorporated organisation.

This required a lot of behind the scenes work from the staff to provide as seamless transition to members.

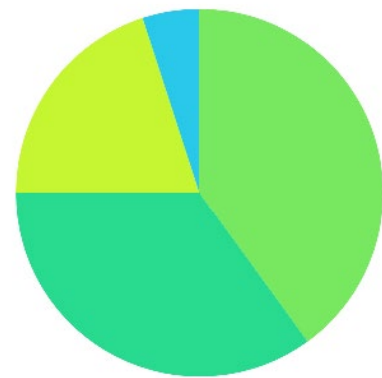
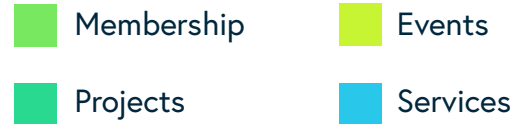
Our work to support the expertise of members from October onwards will be set out in our first annual report as a charity.

Change in status

PIF operated as a not-for-profit company throughout 2023. In July 2023, PIF's application to operate as a charitable incorporated organisation (CIO) was approved by the Charity Commission. PIF's activity was transferred to the new charitable structure on 1 October 2023.

This report covers the activity of the not-for-profit company in 2023. It continued to run in parallel with the CIO until the end of 2023 to complete contracts and finalise accounts.

PIF Ltd's income in 2023 came from four main sources



In 2023 PIF received support from the following corporate organisations



Our services support our members

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. It ensures people and the public get the right information at the right time in their healthcare journey.

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.

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



Eugene Thomas
Website
Manager and
Designer



Klair Bird
PIF Admin



Virginia Chachati
PIF TICK
Engagement
Specialist

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

Joanna Dundon
NHS Wales Informatics
Service

Steph Jury
Guy's and St Thomas' NHS
Foundation Trust

Trishna Bharadia
Owner, The Spark Global

Hannah Ensor
Hypermobility Syndromes
Association

Rachael Middle
Isle of Wight NHS Trust

Tom Bishop
Anthony Nolan

Morag Evans
Library and Knowledge
Specialist

Dr Knut Schroeder
Expert Self Care Ltd

Selina Corkery
Macmillan Cancer Support

Katrina Glaister
Salisbury NHS Foundation
Trust

Dr Juhi Tandon
Cognitant Group

Linda Cowie
FCB Health Europe

Lynsey Hawker
The King's Fund

Dr Alice Wood
GP and Clinical Director

Michele Crooks
Public Health Agency,
Northern Ireland

Join us

PIF is the independent UK membership body for people working in health information and support. We 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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