



Patient Information Forum



Annual Review

2021

A message from the Chair, Sue Farrington



Dear members

This Annual Review marks the end of a five-year strategic period for PIF and the start of our new three-year strategy. The strategy has provided a guide to our activity in challenging times. Achievements have been made in each area (see the timeline on page 5). And in the process PIF has grown as an organisation.

Key developments stand out. The PIF TICK has defined a new standard for trusted health information. PIF's training is CPD accredited and combines with our webinar programme and guidance to develop member expertise in meeting our best practice standards. The evaluation of health information is central to PIF TICK and is the subject of our latest guidance document.

Our Perfect Patient Information Journey (PPIJ) project has produced a tested process to ensure trusted health information is integrated in patient journeys through the health service. As we look to the future we know there is much to do to ensure trusted health information reaches 'everyone', a goal at the core of our vision.

In the last two years more of our activity has focused on health and digital literacy, accessibility, translation, the cultural appropriateness of information and the need for user involvement and co-production. This work will now fall under a new strategic aim 'Inclusion'.

This will sit aside our refreshed aims on 'Quality', 'Expertise' and 'Integration' and will guide our work plan for the next three years. You can read our full strategic aims [here](#).

We would like to thank members for their input in refreshing our strategy and we look forward to working with you over the next three years in pursuit of our vision.

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

2021 began with the darkest days of the pandemic but also with a new hope offered by the rapid roll out of the vaccine programme. Access to trusted health-literate information became a national priority amid a tide of disinformation on COVID vaccination.

Interest in the PIF TICK surged. By the end of the year 85 organisations joined the scheme. The PIF TICK website launched in July to help the public find trusted health information. In December, we joined the Board of the Media and Information Literacy Alliance to work collaboratively on this agenda with other partners.

We continued our work in Nottinghamshire on digital inclusion and completed the PPIJ pilot. We worked with NICE and PRSB on new projects to support shared decision-making. Our Maternity Decisions survey had more than 2,000 responses and showed there is still much to do to put shared decision-making into practice.



1,670
Members
from

250
cross-sector
organisations



16 Corporate partners

1 PIF TICK public facing website



8 Training workshops

187 Trainees



13 Hot topic webinars and events

580 Attendees

2 Reports published



- Maternity Decisions Survey – Results and Recommendations
- Quick Guide to Digital Accessibility

3 Updated guides

- Co-production
- Explaining risks and benefits
- Evidence and referencing



2,215
LinkedIn connections



792,300
Twitter impressions

Our strategic aims 2016 – 2021

Quality

We raise standards and highlight good practice in healthcare information and support.

Integration

We campaign for information and support to be integrated in the patient journey.

Impact

We promote evaluation of health information and support.

Infrastructure

We strive to develop and maintain a sustainable and financially secure organisation.

Expertise

We enhance the expertise of people working in the health information sector.

View our key strategic achievements on page 5 

2016

- Five year strategy sets out PIF's aim on **Quality, Integration, Expertise, Impact and Infrastructure**

- **Perfect Patient Information Journey (PPIJ) phase 1 report published**
- PPIJ pilot project launched at St Mark's Hospital, IBD Service
- Report on Personal Health Records published

2017



2018

- **Perfect Patient Information Journey, phase 2 report published**
- Framework document on health literate decision support tools produced for NHEngland

- Brand refresh and launch of new PIF website
- PPIJ pilot site phase 2 work begins at St Mark's
- NHS Information Standard closes
- **PIF TICK pilot begins with 12-cross sector organisations**
- PIF launches training courses on Writing Health Information and Health Literacy
- Health and Digital Literacy survey launched



2019

- PIF TICK pilot completes
- PIF TICK launches in April with 50 members by the end of the year
- COVID-19 resources hub launched
- **PIF COVID Choices Survey finds patients are avoiding healthcare**
- Health and Digital Literacy Survey published and charter launched
- Digital inclusion project starts with Connected Nottinghamshire
- Guidance on Producing Information for Children and Young People published



2020

- PIF's training becomes CPD accredited
- Quick Guide to Digital Accessibility published
- **PIF TICK website launches**
- PPIJ pilot at St Mark's completes
- **Maternity Decisions report published**
- PIF TICK reaches 85 member organisations
- Strategy review commences in consultation with members



2021



Quality – the PIF TICK

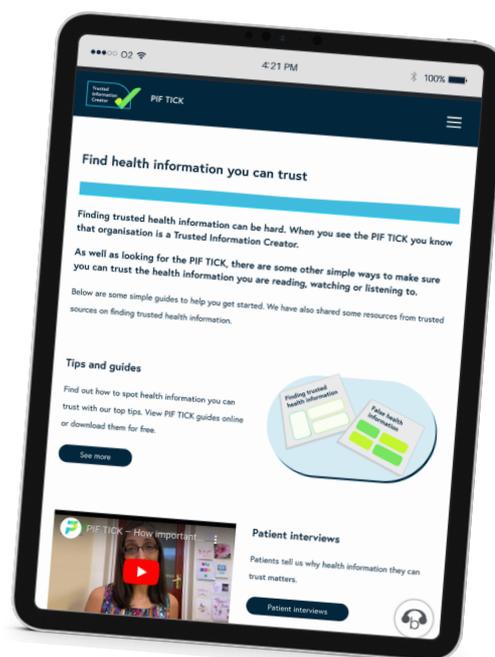
The PIF TICK public-facing website launched in July, 2021, promoting quality, independently-assessed health information to a wider audience.

In its first six months the website, which includes links to all certified PIF TICK members, had 5,000 unique visitors. A public-facing website was identified as a key need by health information producers so we were delighted to deliver this outcome just one year after launching the scheme. The new website received widespread media coverage, in local newspapers, industry publications and on the RNIB podcast.

Membership surges

As the UK's only independently assessed quality mark scheme for both print and online health information, the PIF TICK continued to support our strategic objective to improve the quality of health information in 2021. By December, 85 organisations had signed up and more than 50 organisations had proven they met our 10 robust criteria to gain Trusted Information Creator status. The PIF TICK is recognised by external bodies including HCI video and Healthinote. It is used as part of the vetting process for information from external sources syndicated on their NHS facing platforms.

In 2022 we will be reviewing the criteria to ensure the PIF TICK continues to set the highest possible standards for health information.



It's helped us to identify all the essential elements of a patient info resource, and then to embed them in a production process that is streamlined and flexible.

PIF TICK member

Criteria at a glance

1. Systems
2. Staff training
3. Identifying need
4. High quality evidence
5. Involving users
6. Content
7. Layout and design
8. Feedback
9. Marketing
10. Evaluation

Integration

PIF's work on integration continued in 2021 with demonstration projects in inflammatory bowel disease, scleroderma, maternity care, digital consultations and digital care plans. PIF's Perfect Patient Information Journey methodology underpinned all these projects.

In January we worked with people with cancer on virtual consultations. Their insights were used to develop good practice guides for oncology nurses.



We continued our work with the IBD team at St Mark's where the new diagnosis clinic switched to a virtual setting. The digital information pathway and flare card, developed in partnership with Crohn's & Colitis UK, provided additional support to patients unable to attend face-to-face care.

Despite the challenges of the pandemic we completed the 12-month Quality Improvement Project. The PPIJ process is rooted in working with people with lived experience. We took this approach into a virtual setting in our work with Connected Nottinghamshire.

Tackling digital exclusion

We delivered events for older adults and people from migrant communities to uncover blockers to use of the Notts NHS App. These ranged from digital poverty and language barriers to tone and cultural appropriateness of content. We are working with the team to tackle these issues.

The PPIJ was also used to uncover information gaps in scleroderma, working in partnership with SRUK's members and clinical advisors. The next step is to pool the insight gathered and develop solutions to be tested in clinical settings.

Shared decision making

PIF contributed to national projects designed to support the implementation of shared decision making.

PIF is a member of the oversight group for NICE's standards framework for decision support tools and part of the project board that developed the Professional Records Standards Body's draft standard for shared decision-making. The vital importance of this topic was underlined by the results of our Maternity Decisions Survey.



[PIF Maternity Decisions Survey results](#)

More than 2,300 women took part in the survey, which showed a shocking lack of information to support decision making. We partnered with members Tommy's and Bliss and the charity Birthrights to make recommendations for change.

Expertise

January

Membership survey launched to understand the training and support needs of members

March

Workshop
Health information challenges and solutions

PIF TICK webinar
Moving forward with health information



I'll certainly be considering digital literacy a whole lot more than I was doing – a real eye-opener!

Feedback from health and digital literacy training delegate

May

Webinar
Web accessibility

Training becomes CPD accredited



Training
Writing health information

February

Training
Writing health information

Member consultation event
NICE guidelines on shared decision-making

April

Webinar, guide update and poster – **Co-production: Involving users in developing health information**



Training
Health and digital literacy

June

Poster
Health literacy matters

1 in 6
have very low literacy skills

Workshop
NHS health information teams

Workshop
Health information challenges and solutions

July

Health Information Week

Official launch of the PIF TICK website

Trusted Information Creator



Webinar Introduction to health literacy

September

Training Writing health information workshop



We partnered with NHS Digital on a survey on alternative language provision, covering translated material and accessible formats

November

Webinar How social media can optimise health information



- How-to-guide updates
- Communicating benefits, risks and uncertainties
 - Finding and referencing evidence sources

August

Maternity Decisions Survey launched 2,325 responses



October

Round table Health and digital literacy Our expert panel developed a survey on members' practice on target reading age and use of readability tools

up to **1 million** people cannot speak English well or at all

- Webinars
- Using video in health information
 - Managing health information translations

Training Health and digital literacy

December

Training Writing health information



Webinar and report Maternity Decisions: Being Induced – Main Findings and Recommendations

Impact

Demonstrating that health information makes a difference has been a key strategic aim for PIF.

The PPIJ project at St Mark's was designed not only to make health information improvements but also to evaluate the effectiveness of the changes made.

Evaluation measures were baked into the pilot from the outset. We were supported by NHS England who supplied Patient Activation Measures to help the team monitor the progress of patients attending the new diagnosis clinic.

Crohn's & Colitis UK provided bespoke tracking links for the digital pathway.

COVID-19 and information

COVID-19 had a major impact on the pilot and on the patients taking part. It also disrupted healthcare utilisation data making it difficult to draw comparisons based on service usage.

However, the team were able to look at the impact of COVID-19 on PAM scores of patients as part of the analysis. The results demonstrated the positive overall impact of trusted health information.

Evaluating the impact of health information

The learning from the pilot contributed to the development of PIF's Guidance on Evaluating the Impact of Health Information published in early 2022.

The guidance will help organisations evaluate the impact of their work. This is crucial to the achievement of the PIF TICK, and promotes a cycle of improvement.

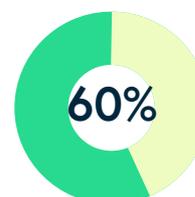
This helps organisations answer the crucial question, Does your information make a difference? We are pleased to note the PIF TICK criteria are having an impact. See stats to the right.



Impact of the PIF TICK



of organisations have made improvements to their information production process



of organisations have started to evaluate their information

Funding

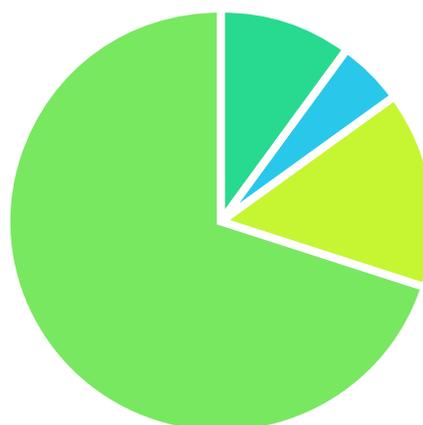
PIF is a not-for-profit organisation.

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

In 2021 PIF's membership grew and it provides a sustainable income stream for the organisation.

Our arrangements are transparent and comply with the Good Practice Guidance produced by National Voices and the Association of the British Pharmaceutical Industry (ABPI).

Where our money comes from



In 2021 PIF received support from the following corporate organisations

abbvie



janssen



NOVARTIS



texthelp™

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



Nicole Naylor
Member
Services
Manager



**Sheena
Campbell**
Communications
Manager



**Arabella
Serrels**
Website
Manager /
Designer

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

Gary Birkenhead
MND Association

Chiara de Biase
Anthony Nolan

Louise Coghlin
Freelance Writer and Editor

Selina Corkery
Macmillan Cancer Support

Linda Cowie
FCB Health

Joanna Dundon
NHS Wales Informatics
Service

Jaina Engineer
Alzheimer's Research UK

Sarah Hennessy
CILIP Health Libraries Group

Katrina Glaister
Salisbury NHS Foundation
Trust

Rachael Middle
Isle of Wight NHS Trust

New members in 2021



Hannah Ensor
Hypermobility
Syndromes
Association



Dr Juhi Tandon
Cognitant Group

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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