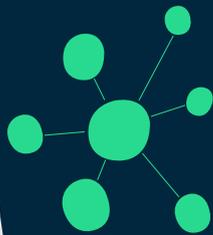
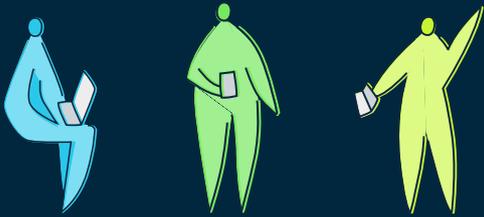




Patient
Information
Forum



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Annual Review

2020

A message from the Chair, Sue Farrington



Dear Members

Never have you, in your role as information professionals, been more needed. If 2020 has shown us anything, it's that trusted, accurate, evidence-based information has the power to help save lives. But get it wrong and it can result in people not seeking the medical help they need, not taking their medication correctly and not accessing the relevant advice and guidance.

Thank you for everything you do to support patients, the public and the wider community. For a long time, we heard at PIF that you often felt your roles were under appreciated and undervalued, but there is now increasing recognition for the importance of your work.

If 2020 has shown us anything, it's that trusted, accurate, evidence-based information has the power to help save lives.

And thank you for your support and engagement in helping us get several key initiatives off the ground last year, despite the challenges we all faced. As a result, the PIF TICK, a quality mark for trustworthy health information, has more than 65 members signed up and the Health and Digital Literacy Charter has gained real traction. Both of these initiatives speak to the importance of meeting quality standards so that healthcare information is accessible and inclusive.

You have also been very generous with your time speaking and participating in webinars, as well as sharing resources and advice with the rest of the PIF community.

Trustworthy health information is key to protecting both personal and collective health. Working together we will ensure that it is a cornerstone of patient and citizen participation in their healthcare and self-management.

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 responded rapidly to the pandemic by creating the Covid Resources Hub, taking training online and producing a series of free webinars to support members.

At a time when access to trusted health information was vital, we launched the PIF TICK quality mark, published the Covid Choices report and campaigned on health and digital literacy.

50+ orgs. joined the PIF TICK

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1,000 members from **300** cross-sector organisations

10 corporate partners

3 reports published

- Covid Choices
- Producing Health Information for Children and Young People
- Health and Digital Literacy Survey Findings

1 Health and Digital Literacy Charter and campaign

1 COVID-19 resources hub

4 training workshops

85 trainees

12 hot topic webinars and events

530 attendees

2,000 LinkedIn connections

844,500 Twitter impressions

It has felt like PIF has really been there to support information providers during the pandemic. The opportunity to discuss and the gathering of evidence has been exceptionally useful.

PIF member

Our strategic aims

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.

Quality – the PIF TICK

The PIF TICK – the UK-wide quality mark for health information – launched in May 2020 following a successful pilot.

The launch coincided with a peak in interest in trustworthy health information, but the PIF TICK had been a year in planning. A six-month pilot with 12 cross-sector members tested the scheme's criteria and assessment process. Public consultation in early 2020 showed strong support for a quality mark to signpost trustworthy health information.

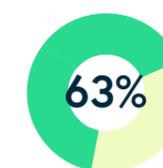
To achieve the PIF TICK an organisation must show its information production process meets 10 criteria in an assessment. Despite the strain on information teams in 2020, more than 50 organisations had signed up by December. PIF had to switch to virtual assessments but 100% of PIF TICK members felt the assessments worked well.

In 2021, PIF will launch a public-facing website to raise awareness of the PIF TICK with tips on finding trustworthy information.

The PIF TICK is central to our strategic objective to improve the quality of health information.

Great scheme. Easy-to-follow process. Supportive assessment. Very efficient and effective. Useful feedback to help us improve our processes.

PIF TICK member



63% of members thought the scheme had improved their production process



90% of members described the assessment as both robust and supportive

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

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Integration

The integration of information into people's healthcare journeys was severely disrupted in the pandemic, bringing to the fore issues of health literacy and digital exclusion.

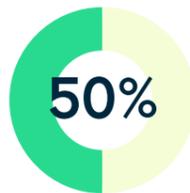
PIF ran a member survey on health and digital literacy in late 2019. The results found only 13% had a health literacy strategy in place and 50% carried out an equalities impact assessment of digital tools.

An expert panel reviewed the findings in Summer 2020. Recommendations published in October called on organisations to become health and digital literacy friendly. More than 60 have since signed up to a charter supporting this objective.

Shared decision-making

PIF is working with our partners the Professional Records Standards Body and NICE on projects to support shared decision making. Our aim is to ensure accessible health-literate information is embedded in standards and guidelines.

This objective was the key priority of members at our Challenges and Solutions Workshop in November. We published the Health Literacy Matters poster in response to members' demand in December.



50% of members carried out an equalities impact assessment of digital tools



13% of members had a health literacy strategy in place

Connected Notts and PIF

Digital health literacy underpins key elements of the NHS recovery plan including virtual consultations, patient initiated follow up (PIFU) and shared decision-making.

PIF was appointed by Connected Nottinghamshire/NHSX to work with communities at risk of digital exclusion on the development of digital care plans and questionnaires to support PIFU. By the end of 2020, the first focus group with older adults had been held.

This project runs into 2021 and uses our Perfect Patient Information Journey (PPIJ) methodology, adapted to a digital setting. PPIJ projects continue in other disease areas (see page 7).



Impact

Access to trustworthy health information drives COVID-19 concern

PIF's Covid Choices survey was launched in July with the support of our partner Norgine. More than 800 people responded. The survey asked the public about access to trusted information on COVID-19 at a point when government messaging was seen as confused.

PIF's Covid Choices report was published in September with recommendations to encourage people back to care. It generated ongoing media coverage including a CPD feature in Pulse.



1 in 3 were avoiding GP and hospital services because of concern about COVID-19

A sub analysis found the biggest factor influencing people's COVID-19 concern was access to trusted health information.

The result provided evidence of the value of health information.

Impact study at St Mark's Hospital

Early findings from the Perfect Patient Information Journey at St Mark's IBD service were presented at a Parliamentary showcase in mid-March. Weeks later the hospital was hit hard by COVID-19. The project continued using virtual clinics. Patients already had a 'flare card' to support self-management. This was developed at the end of 2019 in partnership with Crohn's & Colitis UK. The impact of the St Mark's project is now being assessed. PIF will publish the findings of the project in 2021, along with guidance on how to evaluate the impact of health information, supported by a new CPD-accredited training session.



PIF Director Sophie Randall and Dr Lovesh Dyal

Infrastructure

PIF is a virtual organisation and adapted quickly to lockdown.



We made changes to our team to respond to new priorities. Dan Wills (left) joined PIF as Quality Mark Manager in March.

Dan led the successful launch of the PIF TICK, taking the scheme to more than 50 members by the end of the year. Sophie Randall became Director and Nicole Naylor Head of Member Services. Sheena Campbell continued as Communications Manager and Arabella Serrels as Administrator and Webmaster.

Expertise

January

Writing health information training workshop

The course was well structured and it has left me feeling more positive about my role and the possibility of improving what we do.

Feedback from event attendee

March

4 March
PIF's last face-to-face event:
Using digital tools to maximise health information

23 March
COVID-19 lockdown

May

Official launch of the PIF TICK

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

February

Dan Wills joins PIF to lead the PIF TICK scheme

April

PIF's first webinar:
Maintaining the quality of health information in reactive situations.



Speakers from NICE, Mind (Helen Leech, right) and ShiftMS.

The free events/webinars are hugely appreciated at the moment.

Feedback from event attendee

June

Risk communication and COVID-19 masterclass: Webinar with Dr Alexandra Freeman, Winton Centre for Risk & Evidence Communication



July

Health Information Week Partners



Writing health information
PIF's first virtual training

Remote user engagement
webinar with speakers from NRAS and PRSB

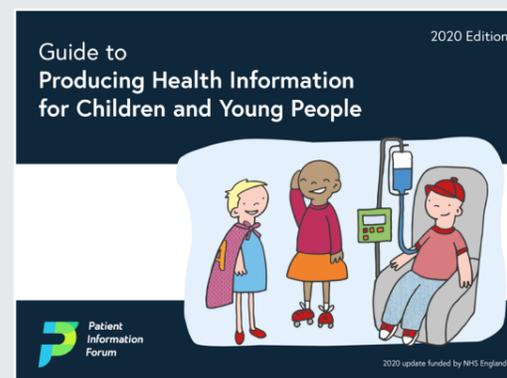
September

Report: Covid Choices Survey results



November

Updated guidance: Health information for Children and Young People



Online workshop: Health information challenges and solutions

August

Round table on health and digital literacy

Expert panel:

- Julia Bell, Patient Information Consultant
- Jonathan Berry, NHS England
- Stacey Budd, Gloucestershire Hospitals NHS Foundation Trust
- Ruth Carlyle, Health Education England
- Louise Coghlin, PIF Advisory Group
- Sue Farrington, Chair of PIF
- Jaina Engineer, Crohn's & Colitis UK
- Alexis Farrow, Connected Nottinghamshire
- Bob Gann, Digital Exclusion
- Aiden Kelly, TextHelp
- Jo Protheroe, Health Literacy Group UK

October

Health and digital literacy report and charter launched

- ✓ Assess the equalities impact of digital projects
- ✓ Easy to understand information
- ✓ Easy to use print and digital projects
- ✓ Co-produced with users
- ✓ Trained staff in health literacy

December

Webinar: What have we learned this year? Speakers from BME Cancer Communities (Rose Thompson, right) Patient Safety Learning and the Winton Centre



Health literacy matters poster



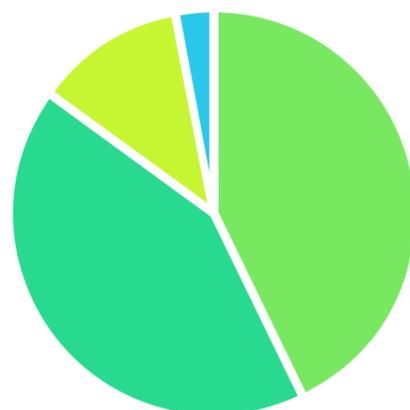
Funding

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.

Our industry partnership scheme and project funding provides around 50% of our income.

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 2020 PIF received support from the following corporate organisations



The comments from PIF were very helpful. Delivering the Sounding Board at the peak of the holiday season to meet an urgent deadline was much appreciated.

Swati Jha, Consultant Urogynaecologist

Our services support our members

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 allows members to learn from one another, saves time and prevents reinventing the wheel.

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

Governance

Our board

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

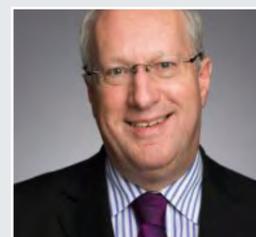
In 2020 these were:



Sue Farrington
Chair



Anne Ballard
Non-Executive Director



Graham Parker
Non-Executive Director



Jacquie White
Non-Executive Director



Keep communicating on social media and keep raising the profile of PIF.

PIF member

Advisory group

PIF is guided by an advisory group of members.

In 2020 these were:

Gary Birkenhead
MND Association

Kate Betteridge
Neil Betteridge Associates

Chiara de Biase
Anthony Nolan

Selina Corkery
Macmillan Cancer Support

Joanna Dundon
NHS Wales Informatics Service

Enid Povey
NHS Digital (stepped down)

Dr Knut Schroeder
Self Care Forum

Louise Coghlin
Freelance Writer and Editor

Linda Cowie
Freelance Consultant

Sarah Hennessy
CILIP Health Libraries Group

Katrina Glaister
Salisbury NHS Foundation Trust

Rachael Middle
Isle of Wight NHS Trust

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



Published by the Patient Information Forum
483 Green Lanes, London, N13 4BS

pifonline.org.uk
info@pifonline.org.uk

