



Patient Information Forum



Annual Review 2019

A message from the Chair, Sue Farrington



Dear Members

I want to thank you all for your passion and dedication to improving the healthcare experience of patients and the public through your commitment to producing high-quality, accessible, evidence-based healthcare information. It is the cornerstone of patient-centred care, shared decision-making and self-management.

Healthcare information provides a foundation, allowing patients and healthcare professionals to engage in a shared partnership to improve health outcomes and enable people to better manage their health and care.

Four years ago, we set out an ambitious strategy to transform our approach to addressing the challenges we faced in shifting the on-going conversation about the importance of healthcare information into something more tangible. I am pleased to report that we have made excellent progress, taking practical steps towards information becoming embedded into the patient pathway through the development of the *Perfect Patient Information Journey* model, which can be adapted across all condition and service areas.

Supporting and driving up quality is a strategic aim and has always been at the heart of PIF, and so in 2019, we were delighted to have the support of Bupa UK to develop a Quality Mark for Healthcare Information. I would like to thank the twelve organisations who worked with us to develop and pilot the PIF TICK, which has been well received across all sectors.

PIF would not be PIF without you, our members. It is your ideas, expertise and support that has helped to define and shape the organisation we are today. We look forward to continuing this partnership.

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



1 new website



1 brand refresh



12 organisations joined the PIF TICK pilot



14 corporate partners



1,100 members from 300 cross-sector organisations



2,000 LinkedIn connections



10 events

3 pieces of guidance published



348,500 Twitter impressions



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

In 2019 PIF piloted a Quality Mark for health information to recognise high standards in the production of health and patient information.

The pilot scheme was made possible through funding by Bupa UK.

The quality mark is based on organisations meeting 10 key criteria. These were developed in consultation with our cross-sector membership.

The 10 criteria are:

1. Health information is created using a consistent and documented process.
2. Staff are trained to produce high-quality information.
3. Information meets an identified need.
4. Information is based on sound evidence.
5. Patients are involved in the development of health information.
6. Information is written in plain English.
7. Print and digital information is easy to use and navigate.
8. Users can give feedback on information.
9. Information is promoted to ensure it reaches those who need it.
10. The impact of information is measured.

Going through the process has helped improve the quality of patient information provided in our Trust.

Joanne Sims, The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust

The PIF TICK was piloted by 12 major health organisations:



felt the scheme helped maintain or improve internal processes and procedures



would recommend the scheme to other organisations

Consumer research

Consumer research found 80% of the public would look for a quality mark on health information. Trust and ease of understanding were top priority for the public. They identified a 'tick' as the best symbol to represent these values.

Trusted Information Creator



Patient Information Forum

Integration

The Perfect Patient Information Journey

PIF's ongoing Perfect Patient Information Journey (PPIJ) project is supporting twin strategic objectives to integrate health information along patient journeys and measure the impact it has on patients and health outcomes.

In 2019 we started the PPIJ pilot project at St Mark's Hospital. Information gaps identified in the first phase are being addressed by information innovations including a new diagnosis clinic; a flare card; a patient booklet review; and better signposting to Crohn's and Colitis UK's resources.

The impact of these changes is being evaluated using Patient Activation Measures

(PAM), healthcare utilisation data and tracking links to Crohn's and Colitis UK's information. Funding has been provided by AbbVie and NHS England has provided Patient Activation Measure licenses to support the project.

The Dorset Cancer Partnership's Dorset Macmillan Cancer Information Project used the PPIJ process to help structure its insight work for a new web-based information service. PIF also provided consultancy advice on impact measurement.

The full report and findings of the PPIJ project will be launched at a PIF event in November 2020.

It's been a very interesting and insightful experience. It gave us the opportunity to reflect on patient information and its role in disease management. I found the PIF team to be very knowledgeable with good insight into patients' needs, and I thoroughly recommend them to future services.

Dr Naila Arebi, Consultant Gastroenterologist, St Mark's Hospital



Impact

Member survey on impact and evaluation

More than 50 organisations responded to our survey on measuring the impact of health information. Of those using validated measures, 50% were able to demonstrate a positive impact on outcome and 48% a partial impact. This provides powerful evidence of the positive impact of patient information and valuable return on investment. Overall, 88% measure the impact of the information they provide.

How responding organisations measure impact



Validated measures used:



Influencing: advisory groups and panels

- BMA Patient Information Awards – Judging Panel
- Health Education England's Health Information Week – Advisory Panel
- Janssen – Patient Advisory Group
- NICE – Member of the Shared Decision-Making Collaborative
- Professional Records Standards Body – Advisory Group
- National Institute of Personalised Care – Member

Infrastructure

In 2019 PIF had a brand refresh and launched a new website in response to member feedback.

The new website offers better navigation, a smoother user experience and provides a fresher, more modern look. It also allowed

us to implement a powerful new tool putting digital accessibility in the hands of our members and website visitors. YouAccess has easy-to-configure settings enabling visitors and members to tailor pages to their needs. The new website also features Browsealoud software, supplied by our partner Texthelp.

Expertise

January

Event:
Behaviour Change and Health Information



February

Executive Circle on Digital Health Records



March

Event:
Working with Seldom Heard Groups

April

Updated Guidance:
How to communicate benefits, risks and uncertainties



May

Round Table
on App development



Advisory group member Knut shares his experience of app development

June

Event:
Involving Users in Health Information



July

New Guidance:
Involving users in developing health information



September

Workshop:
Health Information Challenges and Solutions



Updated Guidance:
Finding and referencing evidence sources

November

Round Table on the new PIF TICK



Training workshop:
Health Literacy

Event:
Producing Information for Children and Young People

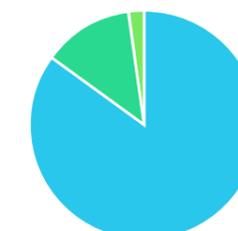


August

Health Literacy Survey launched

How important do you think it is to consider health literacy when you are planning, developing or writing information resources or services?

- extremely important
- very important
- quite important



October

Training event:
Writing Health Information



December

NHS England confirms update of guidance on Producing Information for Children and Young People for 2020



The information learnt at this event has been invaluable in forming ideas on how we take the provision of patient information forward.

Feedback from event attendee

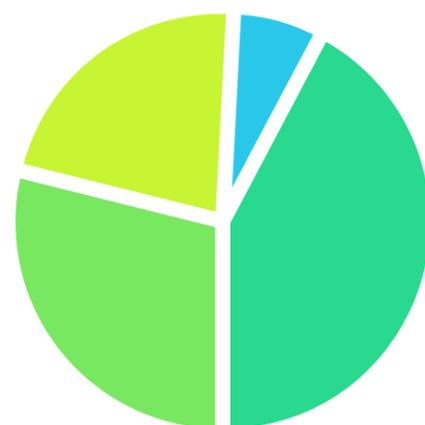
Funding

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 2019 PIF received support from the following corporate organisations



We advertised with PIF for a freelance editor to review our suite of information about children's lung health and were delighted by the number and quality of the responses.

Judith Rogers, Editor – British Lung Foundation

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.

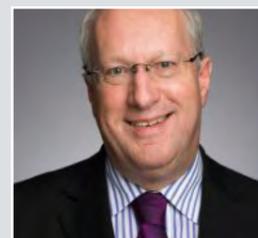
In 2019 these were:



Sue Farrington
Chair



Anne Ballard
Non-Executive Director



Graham Parker
Non-Executive Director



Jacquie White
Non-Executive Director

Maeve Hully
Non-Executive Director
Stepped down in July 2019

Advisory group

PIF is guided by an advisory group of members.

In 2019 these were:

Gary Birkenhead
MND Association

Kate Betteridge
Neil Betteridge Associates

Chiara de Biase
Anthony Nolan

Joanna Dundon
NHS Wales Informatics Service

Enid Povey
NHS Digital

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

Anna Leibowitz
Macmillan Cancer Support

Rachael Middle
Southern Health NHS Foundation Trust

Join us

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

We have more than 1,000 members in 300 cross-sector organisations. These include national charities, the NHS, commercial, government, freelance and academic sectors.

Together with our members 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 joined because PIF had some brilliant events coming up that I knew would support my knowledge development around digital patient information, and I've happily been a member since.

Jen Clifford, PIF member

Our Partners



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