Patient Information Forum

Perfect Patient Information Journey:

7 steps for health services to improve information for people with long term conditions

pif

Patient Information Forum

For everyone involved in health information and support

Contents

The Patient Information Forum (PIF) is the UK membership organisation and network for everyone working in, and involved with, healthcare information and support.

We are committed to improving the healthcare experience of people across the UK. We do this by supporting individuals and organisations to provide person-centred, high-quality and accessible information, which supports people to understand and make informed decisions about their health, wellbeing and care choices.

PIF is a non-profit, independent organisation with members in all healthcare sectors and in every country in the UK. We influence to ensure the quality of health information is high up on the agenda and champion the expertise of those working in this field.

PIF provides a range of services for its members and the wider health information community. These include a weekly email newsletter, events, guides, query service and online groups.

To find out more about PIF, our work and our members go to:

🌐 www.pifonline.org.uk

✉ admin@pifonline.org.uk

🐦 @PiFonline

in patientinformationforum

Please note: This interactive PDF can be viewed in a browser but will work best when viewed in Adobe Acrobat.

Download the latest version of Adobe Acrobat Reader here.

We welcome your comments and suggestions about this publication

By giving us constructive feedback, and sharing any related research or projects you are aware of, you can help us to produce higher quality and more relevant information in the future.

If you would like to give your feedback, contact us at admin@pifonline.org.uk.

Acknowledgements

Patient Information Forum

For everyone involved in health information and support

High-quality, clearly-communicated, evidence-based healthcare information, which is accessible and developed with its users, should be embedded throughout all care pathways in the NHS and the private sector. It should form part of every interaction between a patient and their healthcare professionals (HCP).

Ensuring people are well informed about their health condition, their treatments and choices, and what they can do to stay healthy is of huge benefit to patients, improves outcomes and helps to relieve pressure on the health service.[1] These are all points endorsed in the recent NICE 'Shared Decision-Making Collaborative, A Consensus Statement'.

This is particularly important for the 15 million people in the UK[2] who are living with long-term conditions. After all, most will be managing their own condition every day, probably only seeing doctors or nurses every few months unless they are experiencing acute problems. Having access to health literate, high-quality information, in the right format, at the right time, is vital to support patients to self-manage and to take an active part in making shared decisions about their treatment and care.[3]

At the Patient Information Forum, we know this can appear to be a daunting task. Every patient's information needs are different depending on their condition or conditions, age, lifestyle, health literacy level and a multitude of other factors. Also, people's needs change over time. This may be because of changes in their condition or changes in their life.

However, we know the status quo is not good enough. Although the need for high-quality patient information has been embedded in policy for the last 15 years our research shows people do not have enough information to look after their health.[4]

Much of our previous work has identified the need and provided the evidence for better patient information. This report provides very practical guidance to health services and other providers on how to make sure this happens in practice. It recommends a practical process to identify and close gaps in patient information pathways.

Sue Farrington
Chair of the Patient Information Forum

The pilot studies in this report demonstrate 7 steps for health services to embed high-quality, easy to understand information across patient journeys.

By putting patient information needs at the forefront of service planning and by thinking about the 'Perfect Patient Information Journey' for patients, healthcare professionals can ensure that individual patients receive the right information, in the right format, at the right time.

The two key things we know are needed are time and leadership. Time to listen to patients about what they need, to map the pathway, identify and plug any gaps. Leadership to make sure everyone in a service knows their role regarding patient information, to make sure it is a priority and to ensure it happens.

We would like to see every healthcare service adopt our 'Perfect Patient Information Journey' and use the 7 steps to embed and signpost high-quality, easy to understand and simple to access information for patients when they need it. This report is a first step towards that goal.

"We would like to see every healthcare service adopt our 'Perfect Patient Information Journey' and use the 7 steps to provide high-quality information for patients."

1 NICE, Shared Decision-Making Collaborative, A Consensus Statement. September 2016

2 Department of Health, '2010 to 2015 government policy: long- term health conditions'. Available at www.gov.uk/ government/publications/2010-to-2015-government-policy- long-term-health-conditions/2010-to-2015-government- policy-long-term-health-conditions

3 Patient Information Forum, Making the Case for Information. The evidence for investing in high-quality health information for patients and the public, 2013 www.pifonline.org.uk/wp-content/uploads/2014/11/PiF-Case-for-Information-Report-Final-Full-Report.pdf

4 Patient Information Forum, Is knowledge power? Using information and support to empower patients, 2015 www.pifonline.org.uk/wp-content/uploads/2015/03/Is-knowledge-power.-Using-information-and-support-to-empower-patients.pdf

PATIENT SUPPORT GROUP

1. Executive Summary

With more than 15 million people living with one or more long-term condition in the UK, it is vital that patients are supported with high-quality, accessible healthcare information to enable self-management and to support them to make shared decisions about their treatment and care.

Embedding high-quality, accessible healthcare information across all patient pathways will enhance patient experience, improve outcomes and support patients with long-term conditions to manage their health. This will help tackle health inequality by empowering more people to make informed choices about their health and care.

The Patient Information Forum has developed 7 steps to support healthcare services to develop and embed patient information across their pathways. By using this process, services can create a 'Perfect Patient Information Journey' and transform the information experience of patients in a matter of months.

The 7 steps are:

1-2 months

1. Get the leadership team on board and clarify roles
2. Find out what your patients think
3. Find out what your staff think
4. Map the current patient information journey and identify gaps

3-4 months

5. Identify and make improvements

10-12 months

6. Evaluate the impact of changes made

Annually

7. Benchmark, review and maintain patient involvement in implementation of change.

"By using this process, services can create a 'Perfect Patient Information Journey' and transform the information experience of patients in a matter of months."

This report includes experiences of two pilot studies in implementing the 7-step process; an inflammatory bowel disease (IBD) service and a hospital Trust. Both pilot studies demonstrate the importance of investing time in the process and in having clear leadership to drive improvements across an organisation.

The IBD pilot study shows how a wide range of information needs were revealed through the process of gaining patient and staff insights. The hospital Trust pilot highlights the importance of getting senior leadership on board from across the organisation, in order to change the culture of the organisation and to start to prioritise patient information.

This report draws on the experience from the pilot sites, a range of focus groups with patients and healthcare professionals (see appendix) and the evidence review and insight work conducted as part of the 'Perfect Patient Information Journey: Phase 1 report'. The findings of both phases of the research have resulted in the following recommendations.

'Perfect Patient Information Journey' - Recommendations

☑ **Information should be at the forefront of healthcare service planning and delivery**. To ensure this happens, services should consider a patient's information flow across their pathway by using the 7-step 'Perfect Patient Information Journey' process.

☑ Healthcare services should ensure they have appointed a **named senior level Patient Information Lead** to ensure patient information is high-quality, easy to understand and accessible.

☑ Healthcare professionals should **signpost patients to high-quality, accessible sources of information** throughout their patient journey.

☑ **Patients should be supported to ask questions** to help them to take an active part in their care and share decisions, for example through decision aids or checklists.

☑ Services should **evaluate the impact of the information** they are providing and make improvements where identified.

☑ **NHS England and the Care Quality Commission, NHS Scotland, NHS Wales and Department of Health in Northern Ireland should set clear national standards** for information provision for healthcare services.

☑ **Industry, the NHS and advocacy groups** should form partnerships to identify and create high-quality information mapped to the key points on a 'Perfect Patient Information Journey' in individual long-term conditions.

Develop a 'Perfect Patient Information Journey' with the Patient Information Forum

PIF's expertise in facilitating the development of a 'Perfect Patient Information Journey' using the 7-step process is available on a cost-effective, not-for-profit consultancy basis to NHS Trusts and other bodies.

- PIF can provide the knowledge and expert capacity to work with your staff teams and gain deep insight from patients, including hard to reach groups.

- PIF's independent and supported facilitation of the 7-step process allows services to look at patient information provision in a constructive and planned way creating new partnerships with advocacy groups.

- PIF's toolkits and guidance can be used to create high-quality information where information gaps are identified.

- PIF's Sounding Board service can provide an external review of both new and existing resources.

- PIF's project team will ensure implementation stays on track and objectives are measured when your internal capacity is stretched.

For further information contact:
Sophie Randall, Project and Partnership Manager sophie.randall@pifonline.org.uk

"It's been a very interesting and insightful experience for the whole team. It gave us the opportunity to reflect on patient information, its role in disease management and how information is communicated to patients.

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 on the PIF facilitation of the 7-step process at St Mark's Hospital.

For someone living with a long-term condition, a 'Perfect Patient Information Journey' will ensure that they are well informed about their condition, their treatment, their options, expected progression, and how they can best manage their illness. It will mean information is given to them in formats they understand, at times when they need it and can process it and will support them to ask questions along the way.

For services, the 'Perfect Patient Information Journey' is an approach that puts a patient's information needs at the forefront of health planning and service delivery. It considers a patient's information needs holistically across their journey taking into account changes in their condition, e.g. new treatments, disease progression, possible surgery, how to manage symptoms or side effects and lifestyle tips. It also takes into account changes not relating directly to their condition, such as having children, travelling or managing another condition. A patient may need the same information many times or may need much more detailed information as they get used to living with their condition.

Critically, developing a 'Perfect Patient Information Journey' must have the individual patient and their needs at the centre. An individual's health literacy, language needs, internet access and preferred methods of receiving information, must all be taken into account.

Patient-centred care

At the Patient Information Forum, we believe that developing a 'Perfect Patient Information Journey' is the foundation for person-centred care, shared decision-making, self-management and patient activation for people with long-term conditions.

If services put patient information needs at the forefront of their planning, and if patients are supported to make sure their needs are met, then both patients and the NHS will benefit.

In May 2017, the Patient Information Forum published a report based on available academic evidence and focus group discussions with patients and healthcare professionals to identify what is necessary for a 'Perfect Patient Information Journey'.

May 2017

Patient Information Forum

Perfect Patient Information Journey: Phase 1 Summary Report

pif Patient Information Forum
For everyone involved in health information and support

www.pifonline.org.uk

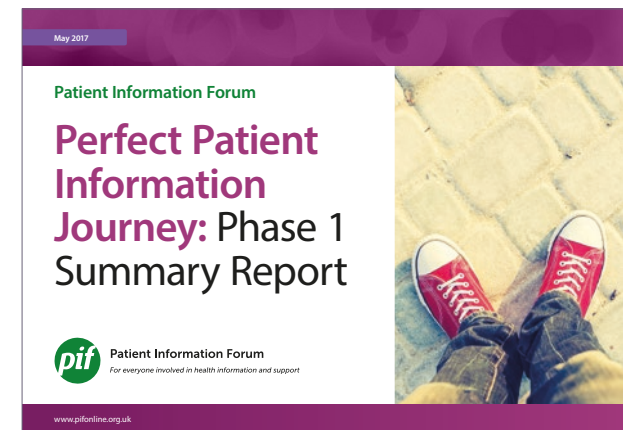"Developing a 'Perfect Patient Information Journey' must have the individual patient and their needs at the centre."

The 'Phase 1' report identified 10 key points. These are:

1. Information on first diagnosis is essential.

2. Information on first diagnosis can also be overwhelming.

3. Information needs change as people move along the pathway.

4. Every patient pathway is different, but there are certain points along each pathway where information is essential.

5. Information must be tailored to the needs of the individual.

6. Being supported to ask questions is vital.

7. 'Dr Google' can be a problem, but patients generally know how to filter online information.

8. Local leadership and information champions are needed.

9. Healthcare professionals want to do more, but time is a barrier.

10. Commissioners want to do more but need the evidence.

Based on these 10 key points, additional focus group research and pilot studies at St Mark's Hospital, North West London, and Hereford County Hospital Trust, the Patient Information Forum has developed a 7-step approach to help health services to develop a 'Perfect Patient Information Journey' for their service users.

The results demonstrate it is possible to create a 'Perfect Patient Information Journey' by following this process.

"Health information is too complex for the literacy capability of **43%** people and the numeracy capability of **61%** of people."

Importance of taking into account health literacy

Up to 61% of working age adults in England find it difficult to understand health and wellbeing information, according Public Health England (*Improving health literacy to reduce health inequalities, 2015*). Health information is too complex for the literacy capability of 43% people and the numeracy capability of 61% of people.

This leaves millions of people excluded from making informed decisions about their health and puts the NHS at risk of litigation.

➲ See the 'Health literacy "How to" guide', by Health Education England, for tips on how to improve your verbal communication skills (e.g. using 'teach back' methods), how to write in plain English, and how to design information that is easy to understand.
www.hee.nhs.uk/our-work/health-literacy

Shared decision-making - a legal requirement

The Health and Social Care Act 2012 placed a new duty on the NHS to promote the involvement of patients in decision-making about their own treatment.

The judgment in Montgomery v Lanarkshire Health Board 2015 placed clinicians under a duty to ensure that patients are aware of any 'material risks' involved in a proposed treatment, and of reasonable alternatives.

Shared decision-making improves decision quality and patient satisfaction and, in some cases, results in more cost-effective care (NICE, 2016). However, in 2016 only 56% of hospital in-patients felt involved in decisions about their treatment (Hoffman, 2017).

➡ There are a range of decision aids available for many conditions to support patients and clinicians in making shared-decisions. See the NICE website for more details. www.nice.org.uk
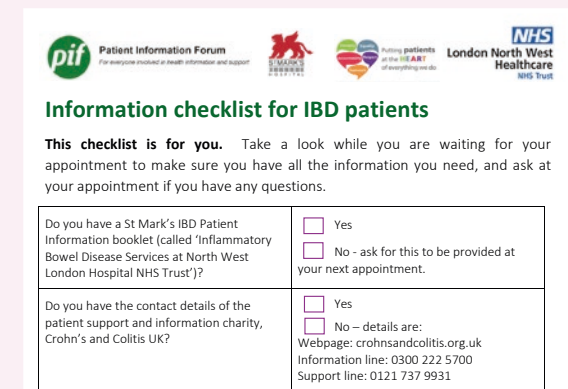
Supporting patients to ask questions: an information checklist for patients

A recurring theme in many of the patient focus groups we held was, as a patient, "you don't know what you don't know". Many patients said that they wanted to be supported to ask questions in order to make the most of their precious appointment times.

In partnership with patients and healthcare professionals, the Patient Information Forum developed an information checklist for patients. This is a series of straight-forward questions for use by people with long-term conditions throughout their patient journey, to support them in accessing the kind of information they require, to play an active role in their care and to support them to make shared decisions with their clinicians.

It contains a series of questions and prompts designed to support the user in accessing the information they may need at that specific juncture of the pathway.

For more details, or to work with PIF to develop a tailored checklist for your service, please contact Sophie Randall at PIF: sophie.randall@pifonline.org.uk.

Example of a patient information checklist, designed for patients to use in the waiting room of an IBD outpatient service

4. The 7-step process to develop a 'Perfect Patient Information Journey'

Health services can develop a 'Perfect Patient Information Journey' by following these 7 steps:

1. Get the leadership team on board and clarify roles

Ensuring the leadership team of a service understands the value of information to patients is a critical first step in changing the culture and embedding information throughout the pathway.

In busy, complex services, having clear roles and responsibilities amongst the staff for information provision is critical. Think about:

• Who will lead this 7-step process?

• Who will make sure all staff know what is available?

• Who can review available patient information resources from other sources and approve them?

• Who will be responsible to embed patient information within care pathways?

1
Get the leadership team on board and clarify roles

2
Find out what your patients think

3
Find out what your staff think

4
Map the current patient information journey and identify gaps

5
Identify and make improvements

6
Evaluate the impact of changes made

7
Benchmark, review and maintain patient involvement in implementation of change.

Annually

1-2 months

3-4 months

10-12 months

2. Find out what your patients think

To create a 'Perfect Patient Information Journey', you must find out what your patients think of the current information provision and ask them what they would like and when they would like it.

- Have they experienced gaps?

- Have they found useful resources elsewhere that they think other patients would benefit from?

- What formats work for them?

Surveys, focus groups and one-to-one interviews are needed to get a good understanding of the needs of your patient group.

- Surveys will give a useful overview and broad statistics of what your patients think about the information they receive and what unmet needs they have.

- Focus groups are a powerful way of exploring beyond yes/no or one-line answers. They will enable you to glean lots of ideas and opinions and to get a deeper understanding of what participants think.

- One-to-one interviews can engage some patients who are less likely to volunteer for a focus group and are an opportunity to explore experiences in depth.

When involving patients, it is crucial you engage with a variety of users. Someone newly diagnosed will have different needs to someone who has lived with the condition for 10 years.

Think about the diversity of the people you are seeking opinions from and try to include people with limited literacy skills, people from vulnerable and excluded groups, people who do not regularly use resources, as well as experienced patients.

You can find more tips on user engagement on the Patient Information Forum website at www.pifonline.org.uk.

"Surveys, focus groups and one-to-one interviews are needed to get a good understanding of the needs of your patient group.

It is crucial you engage with a variety of users. Someone newly diagnosed will have different needs to someone who has lived with the condition for 10 years."

3. Find out what your staff think

The healthcare professionals in your service will have important ideas about how the patient information flow could be improved. Their jobs will be easier if there is better information available to support patients and if it is integrated into care pathways.

Bringing together doctors, nurses and others from your service to run a focus group is a good way to help staff to take a step back from their day-to-day work and to reflect and assess the information provision across the patient pathway.

PIF has developed a 'service information checklist' to support services through this process. It is a series of questions designed for a staff team to discuss together, so a plan can be made to address any gaps in information provision and to ensure consistency across the department. It asks questions about leadership and responsibility for information within the department - what information is available and how information is produced - and about the information given to patients on diagnosis, at consultations and at other points in the pathway.

4. Map the current patient information journey and identify gaps

Use the insights from patients and healthcare professionals to process map the current patient information journey.

Think about the information journey 'as is' and 'as you would like it to be' in order to identify what information is available, what the gaps are, what more is needed and what could be improved.

Bring a group of patients and clinicians together for this process mapping exercise.

Identify what you need to change, prioritise and assign action.

Please contact Sophie.Randall@pifonline.org.uk for information on how PIF's consultancy service can support the development of a service checklist/s for health services.

5. Make improvements

Address the gaps that have been identified and make any improvements that have been highlighted.

Use the 'plan, do, study, act' (PDSA) quality improvement method for every change you are making, so that you can evaluate the impact and make further improvements if necessary (see p16).

Look for quick wins, like making sure you are making the most of information boards or screens and high-quality resources available from relevant charities. Investing time in quality-checking resources from other organisations you can signpost to, will mean you have a much broader range of formats of information, such as 'easy read' leaflets or videos.

Critically, once you have made improvements, make sure all staff know what is available and where to find it.

Map the current patient information journey and identify gaps

Use the insights from patients and healthcare professionals to process map the current patient information journey.
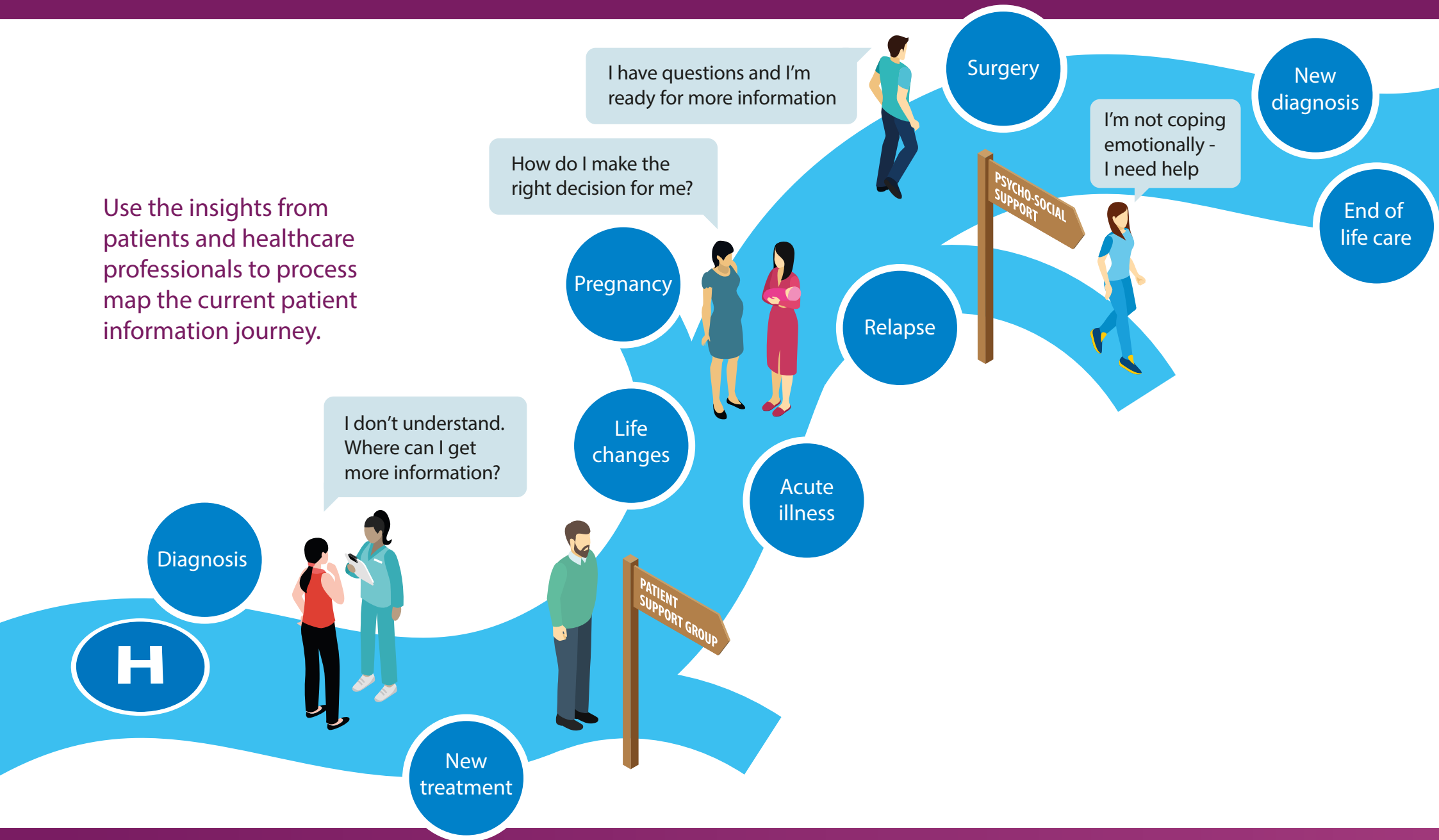
Plan, do, study, act (PDSA) cycles

Plan, do, study, act (PDSA) cycles are recommended by NHS Improvement to test an idea by trialing a change on a small scale, assessing its impact and building upon the learning from previous cycles in a structured way before wholesale implementation.

The four stages of the PDSA cycle are:

Plan – the change to be tested or implemented

Do – carry out the test or change

Study – based on the measurable outcomes agreed before starting out, collect data before and after the change and reflect on the impact of the change and what was learned

Act – plan the next change cycle or full implementation.

See bit.ly/NHSPDSA for more information.

6. Evaluate the impact of changes made

Evaluating the impact of any changes you make is vital to ensure you are improving patient experience and can demonstrate the value of improving information provision. It will also identify further areas where changes are needed, or if there have been any unintended consequences.

As you plan the changes, think about the impact you would like your changes to have. This might be behaviour change, increased confidence and involvement in decision-making in regard to treatment choices, improved ability to self-manage, or confidence and understanding in living well with the condition.

The PDSA method will help you to consider what outcomes you are hoping to see, and how you will collect information before and after the change.

Think of the measures you would use to evaluate impact. The Patient Activation Measure (PAM) is a useful tool to capture changes in patient engagement in managing their condition over time. More information on PAM is available at bit.ly/NHSPAM.

You can find more tips and links on evaluating information on the Patient Information Forum website at bit.ly/PIFevaluate.

7. Benchmark annually and maintain patient involvement

Conditions, services, people, technology and treatments change. Seek opinions from patients and staff regularly on the information provision in your service. Benchmark patient satisfaction annually with information and support provided. Maintain levels of patient involvement in the development of information via patient panels and focus groups.

If possible, link patient information reviews to other service reviews or evaluation activities that take place. This will help to embed the process of reviewing and improving information provision within the service, as a matter of course.

Ensuring there are clear roles and responsibilities for patient information, as recommended in Step 1, will help maintain the focus on patient information to ensure it is up-to-date and reflects the needs of the patient group at all times.

Context: St Mark's Inflammatory Bowel Disease (IBD) service is a specialist and world renowned IBD service and part of the London North West Healthcare NHS Trust. The service encompasses all aspects of IBD care - medical, nursing and surgical treatments, psychological and nutritional support, research and education, as well as a supported process for the transition from child to adult care.

In 2016 the service began a re-design process with the National Institute for Health Research that aimed to establish a more patient-centred care model within the IBD outpatient service, offering patients more choice in their appointment location via a new telephone clinic, and aiming to reduce waiting times for clinic appointments for all patients. As part of this process, leading clinicians decided to review the information provision for patients across the pathway.

Over the course of nine months (June 2017 – February 2018), PIF worked with the service to support the first four of the 7-step process outlined above. This included facilitating a patient focus group and a staff focus group; conducting a patient survey for outpatients;

and co-facilitating a process mapping workshop with patients and staff to map the current information journey and to identify gaps and areas for improvement.

The pilot brought forward useful insights with some recurring themes, such as a consensus around the potential benefits of improving information provision for patients and the need for better signposting to the high-quality, variety of information available through Crohn's and Colitis UK (CCUK).

Information gaps

The patient focus group highlighted the need for more information on diagnosis, the high value of a post-appointment call with a nurse specialist when changes to treatments have been discussed at a consultation, and the need for more practical information for living with the condition, such as dealing with diet, lifestyle changes, stress, and the availability of 'Can't Wait' cards and radar keys for urgent access to toilet facilities.

The staff focus group further identified that there was a need to clarify roles, responsibilities and leadership for patient information in the department.

Staff also identified a lack of resources for vulnerable patients, particularly those who do not speak fluent English, or who have low health literacy.

The patient survey gave a useful snapshot of the awareness of various resources.

For example, of the 33 patients surveyed:

- **Two thirds** (22/32) of people felt they had been given enough information when diagnosed and a third felt they had not been given enough.

- **A third** (12/32) were not aware of the telephone advice phone line.

- **Over a half** (16/28) were not aware of the email advice service.

- **Two thirds** (22/33) of respondents were aware of CCUK, one third were not.

- **Less than a third** of patients (9/31) had been given the St Mark's IBD patient book.

- **Three quarters** (22/29) would find it useful to have more information about self-management and first steps to take during a mild flare.

- **The vast majority** (29/33) of patients said they were happy to access online information. However, a small minority (3/33) said that they would not be able to access online information.

- **Two thirds** (20/30) of patients said that they understood how their condition might progress in the future.

- **Almost half** (15/33) of patients said that they sometimes forget to ask questions at their outpatient appointment.

- **Almost a third** of patients (9/29) did not feel they had enough information about their medicines.

- When asked how well informed they feel about their condition on a scale of 1 to 10 (1 being completely uninformed and 10 being completely informed), **the mean average was 7.6**.

The process mapping workshop drew these insights together and allowed patients and staff to share their experience of the patient information pathway 'as is' and how they would like it to be.

It identified the need for some new resources, as well as simply making current resources more accessible.

For example, the process mapping workshop identified some patients are diagnosed when they have an endoscopy for suspected IBD. Where they have IBD, the endoscopist will usually give the patient their diagnosis and they would then receive a consultant appointment in a few weeks to talk through the diagnosis, consequences and treatments. There was consensus that patients would benefit from more information and good signposting at endoscopy to tide them over until their consultant appointment.

Setting priorities

The process mapping workshop also highlighted support for a 'flare card' to guide patients who are in remission and then start to experience a mild flare, with the right steps to take. This was supported by the results of the patient survey, which showed that three quarters of patients said that they would find it useful to have more information about self-management and first steps to take during a mild flare.

Insights were used to develop the flow chart overleaf which shows the different information resources available at different points of a patient's journey, and additional resources that patients and staff identified and recommended should be introduced in the future.

NHS Greater Glasgow and Clyde has set up a flare care scheme - see case study on page 20.

Pilot project: Developing a 'Perfect Patient Information Journey' with St Mark's IBD Service

Point in pathway	Resources available	Additional resources to consider
New diagnosis **Transfer into St Mark's** **Transfer from paediatrics**	• Diagnosis delivered by a HCP (at endoscopy or at first appointment with a consultant) • Follow up 'new diagnosis' nurse-led clinic appointment • Patients are given a Crohn's and Colitis UK (CCUK) information pack and St Mark's patient information leaflet by a nurse • Transition service	• Basic IBD written information for the endoscopist to give the patient, if they are giving a diagnosis at this point • Updated St Mark's patient information leaflet needs to be completed and distributed
Living with the condition	• Advice Line • Planned regular outpatient clinic appointments (by phone or in person) where nurses give clinical advice and lifestyle information • Written information on 'skin care advice for people with bowel problems' on St Mark's website • Dietary advice via dietitian	• 'Flare card' to support patients in remission to take the right steps when they start to experience a mild flare • More signposting to lifestyle information by CCUK, e.g. radar keys, diet information, information for employers and employees • Ensure all patients have contact details of the Advice Line & how it works
New treatment suggested / starting a new treatment	• Information leaflets on the new treatment • Biologics clinic that brings together clinician, nurse and pharmacist • Azathiropine monitoring leaflet • Psychological support / monitoring as required	• Signpost to / develop audio-visual information • Decision-making aids • Translations of key information to meet the needs of the patient demographics
Investigative tests, e.g. endoscopy	• Verbal information discussion in clinics • Advice Line	• Written information / on website explaining why tests are important; what they test for; what is involved and what patients should expect; how long results take
Surgery	• Verbal information discussed in clinics • Advice Line • Various leaflets	• Consider additional information in leaflet form / on website
Changes in life, e.g. planning a family / travelling	• Crohn's and Colitis UK helpline and leaflets • Fertility addressed at annual open day talks	• Information on IBD and fertility / pregnancy • More signposting to CCUK resources and website and in consultations

St Mark's pilot - the team's perspective

"With an outside perspective PIF were able to explore our application of patient information for IBD patient populations. We found their structured and methodical approach easy to follow and having clear aims reduced the risk of getting lost in the various dimensions of patient information. Through staff and patient focus groups and an evaluation questionnaire followed by timely reports of the outcomes, they gave us a better understanding of our weaknesses and areas for improvement.

Several, and more than anticipated, areas for improvement were revealed by PIF. There was no systemised method to deliver information, as well as no mechanism to record what information had been given to patients. We lacked a disease map on which to provide information as a patient's disease state changes in order to avoid overwhelming patients with irrelevant information."

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

Flare cards - National pilot planned for Scotland

When you have a good idea, it is often the case that someone else in another service has had it too.

A pilot of a 'flare card' at NHS Greater Glasgow and Clyde has proved so successful, that Crohn's and Colitis UK, working with the Scottish Government's Modern Outpatient Programme, is developing it further for use across Scotland. This is part of a range of self-management tools and resources being co-produced between patients and healthcare professionals.

The IBD team at the Royal Alexandra and Vale of Leven Hospitals in the Clyde Valley developed the flare card as a self-management tool.[5] Its impact on service use over a 10-month period in 2016 was compared with a similar cohort of patients over 10 months in 2015. This revealed a significant reduction in IBD and non-IBD service usage, steroid prescribing and unscheduled IBD care in the flare-card supported cohort.

A questionnaire found patients felt the 'flare card' was a viable self-management tool which helped control their IBD, improved medication adherence, reduced symptoms and reflected a feeling of patient-centred IBD care.

The 'flare card' helped optimise Crohn's disease and ulcerative colitis management by harmonising clinician evaluation and patient's self-initiation of therapy and investigation, concluded an evaluation of the scheme.

The National Flare Card will be piloted in two health boards before refining prior to a national roll out later this year.

Contact: seth.squires@nhs.net for information on the Clyde Valley pilot. Contact: Monika.Brzozowska@crohnsandcolitis.org.uk for details of the national pilot for Scotland.

5 Squires SI, Boal AJ, Lamont S, et al. Frontline Gastroenterology Published Online First: doi:10.1136/flgastro-2017- 100807

Context: In February 2018 PIF was asked to facilitate Step 1 of the 7-step process at Hereford County Hospital, bringing key members of the hospital together who had an interest in patient information.

This included senior members of the nursing team, communications team, library service, patient experience team, information governance and cancer information service alongside patient representatives from the hospital's patient panel.

The aim was to bring staff and patients from across the hospital together to consider the current patient information process, policies, responsibilities and resources at Hereford County Hospital, and to make recommendations for improvements to the Trust.

The session highlighted the need for clearer leadership and designated roles around patient information within the organisation. Participants at the session agreed that the policy for patient information needed to be reviewed, updated and relaunched across the Trust so staff and teams understand the

process for developing high-quality patient information and how it can meet the needs of their patients.

Principles that underpin high-quality patient information were discussed and there was a consensus amongst the staff and patients involved that patient information should be addressed and improved across the Trust, with the exception of cancer services which already had a dedicated Information Manager and could provide good practice templates of how to approach patient information for other departments and services.

Patient experience

The need for patient information to be reviewed across the Trust was supported by patient experience feedback which showed the most common topics for complaints in the Trust are around communication and information, in particular a lack of information given at discharge. Patients report a lack of consistency: sometimes they do not receive any information, other times they are overloaded with too much complex information.

"This approach highlighted that currently we do not have a coherent message about what patients want. The current information leaflets may be quite inaccessible for many patients in our department."

Feedback after Hereford workshop

Workshop participants agreed a number of actions and recommendations, and prioritised these using 'dot democracy'.

Agreed initial priorities for the Trust were to assign a designated Lead for Patient Information across the Trust, and clear responsibilities for patient information within each department / service, and the importance of raising the profile of patient information with the Trust Board.

The immediate next steps from the workshop were to develop a position paper for a workshop with the Trust Executive Board, to enable senior leadership to acknowledge and recognise the changes that need to be made.

5. Conclusion

High-quality, clearly-communicated, accessible, evidence-based, healthcare information, that has been developed with its users, should be embedded throughout every pathway across the NHS.

The 7-step process outlined in this report is a blueprint to support services to review and improve their provision of patient information and create a 'Perfect Patient Information Journey.' By having a named senior lead responsible for patient information and conducting insight work with patients and staff, health services will be able to identify gaps in information provision and any additional resources that need to be developed or signposted to.

The pilot studies featured in this report demonstrate that information gaps exist even where patient information is prioritised. Innovative services such as email and telephone support lines will only be used and meet cost effectiveness objectives if patients are aware of the service, understand its purpose and how to access it.

Working with patients to identify their needs also uncovers new ways to allow patients to better self-manage, for example if they suspect a flare. Filling this particular information gap improves care for patients and allows flares to be treated sooner, avoiding more costly interventions.

By evaluating the impact of improvements to information provision on patient experience, outcomes, staff satisfaction and to the NHS, services can continue to make improvements and demonstrate the value of investing time and leadership in improving access to patient information.

The Patient Information Forum believes that this on-going cycle of improvements to patient information across patient pathways will be of significant benefit to patients, healthcare staff and the NHS. Supporting patients to self-manage their condition and share decisions about their treatment and care will improve outcomes for all and has the potential to save the NHS money.

The 7-step process outlined in this report is a blueprint to support services to review and improve their provision of patient information.

This project has involved patients and professionals at the outset and throughout to ensure that the issues identified, and resources developed, respond to the experiences and needs of the project's stakeholders and are useful in real-world situations.

The Patient Information Forum is grateful for the feedback and input from patients and professionals throughout the project at all of the focus groups and consultation events that were held. These include:

- A focus group for patients with a range of long-term conditions, Sep 2016

- A focus groups for health professionals working on long-term conditions, Dec 2016

- Semi-structured phone interviews with commissioners, patients and professionals, Sep - Dec 2016

- An Open Space consultation event with patients and professionals, Feb 2017

- A workshop at the National Voices conference, Feb 2017

- A patient focus group at St Mark's with IBD patients, June 2017

- A focus group with St Mark's IBD nurses and doctors, July 2017

- Meetings with the 'fitness for surgery' staff team at Harefield Hospital, Oct 2017 and Jan 2018

- An 'information process mapping' workshop with staff, patients and the CLARHC team (Collaboration for Leadership in Applied Health Research and Care) at St Mark's, Sept 2017

- Feedback at a meeting of the St Mark's IBD Patient Panel, Nov 2017

- A focus group with staff and members of the Patient Panel at Hereford County Hospital, Feb 2018

The Patient Information Forum

We welcome your comments and suggestions about this guide - by giving us constructive feedback you can help us to produce higher quality and more relevant information in the future. If you would like to give your feedback, contact PIF at: admin@pifonline.org.uk with your comments.

Discover the benefits of PIF membership

Join the only cross-sector network of UK health information producers. Our members work in many organisations including the NHS, national health charities, the voluntary sector, pharmaceutical companies and commercial agencies, and freelance.

If you are not a member of the Patient Information Forum, and would like to find out more about us, please go to: www.pifonline.org.uk or contact PIF at: admin@pifonline.org.uk

Develop a 'Perfect Patient Information Journey' with the Patient Information Forum

PIF's expertise in facilitating the development of a 'Perfect Patient Information Journey' using the 7-step process is available on a cost-effective, not-for-profit consultancy basis to NHS Trusts and other bodies.

- PIF can provide the knowledge and expert capacity to work with your staff teams and gain deep insight from patients, including hard to reach groups.

- PIF's independent and supported facilitation of the 7-step process allows services to look at patient information provision in a constructive and planned way creating new partnerships with advocacy groups.

- PIF's toolkits and guidance can be used to create high-quality information where information gaps are identified.

- PIF's Sounding Board service can provide an external review of both new and existing resources.

- PIF's project team will ensure implementation stays on track and objectives are measured when your internal capacity is stretched.

For further information contact: Sophie Randall, Project and Partnership Manager sophie.randall@pifonline.org.uk

To find out more about PIF, our work and our members go to:

🌐 www.pifonline.org.uk   ✉ admin@pifonline.org.uk

🐦 @PiFonline   in patientinformationforum