Patient
Information
Forum

Phase 3

The Perfect Patient Information Journey

Evaluating the Impact of Health Information

AbbVie has provided funding support for this report.
Editorial control has remained with the project authors.
Published by the Patient Information Forum 2022.

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Introduction:

Sue Farrington, PIF Chair

Evaluating the impact of health information is a vital part of the Perfect Patient Information Journey (PPIJ) and it is the topic of this third and final report on the PPIJ process.

Evaluating impact tells us if we are improving outcomes. It helps us identify new challenges and improve not only what we do, but who we reach.

As information producers we need to know we make a difference to patients and the public. We also need to be seen to be making a difference to our funders.

Evaluation tells us if our information is inclusive and accessible to all, including those who experience health inequality. To do this we need to ask the right questions, in the right way, at the right time. This guide will help you do that.

It will support you to work within the PIF TICK criteria for quality, trusted information and embed the Perfect Patient information Journey process in your work.

It is difficult to isolate the impact of the information you produce when so many other factors can influence health outcomes. Models to help you evaluate within the wider context are included in this guide.

> **Evaluation will tell us if our information makes a difference.**

Adapting to change

As part of the development of this report, PIF ran a demonstration project in partnership with the IBD team at St Mark's Hospital. It tested measures to evaluate the impact of information introduced following the earlier stages of the PPIJ process.

None of us planned for a global pandemic at the midpoint of the 12-month quality improvement programme. The experience of running a pilot through the first wave of COVID-19 taught us projects and linked evaluation plans need to be agile.

The St Mark's pilot and other case studies in this guide will demonstrate the practical application of this guidance. You'll find more examples of good practice in the resources section of the PIF website.

We are very grateful to NHS England and Crohn's & Colitis UK for their support with the evaluation measures used on this final stage of the PPIJ project.

We would also like to thank AbbVie for their long term support of the PPIJ project. Much has changed since we started on this path in 2017. →

Introduction:

Sue Farrington, PIF Chair

Having the commitment of long-term funding for this work has allowed us to adapt to the changes of the last five years and complete the roadmap to the Perfect Patient Information Journey.

In the meantime, by working closely with our membership, we have defined the standard for trusted, high quality health information to complement the PPIJ. Evaluation and a commitment to ongoing improvement is a vital element of the PIF TICK.

Sue Farrington, Chair

PPIJ 1 and 2

The Perfect Patient Information Journey, phase 1 report was published in May 2017. It reviewed the available academic evidence and used focus group discussions with patients and healthcare professionals to identify what was necessary for a Perfect Patient Information Journey.

May 2017

Patient Information Forum

Perfect Patient Information Journey: Phase 1 Summary Report

Patient Information Forum

For everyone involved in health information and support

www.pifonline.org.uk

June 2018

Patient Information Forum

Perfect Patient Information Journey: 7 steps for health services to improve information for people with long term conditions

Patient Information Forum

For everyone involved in health information and support

www.pifonline.org.uk

This project has been supported with an unrestricted grant from AbbVie

The recommendations of the first phase research were applied at St Mark's Hospital, North West London. The results were published in 2018 in the PPIJ phase 2 report. It identified a 7 step process to help health services improve information for people with long term conditions.

View PPIJ 1 and 2 at pifonline.org.uk/projects/project-ppij

Project team

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Why evaluate impact?

Evaluation is a key step in the Perfect Patient Information Journey (PPIJ) cycle, which is founded on the principle of ongoing quality improvement. It is only possible to maintain progress if you understand what you have achieved to date.

Evaluation is a key component of the development of quality information. It is embedded in the criteria for PIF's quality standard for health information, the PIF TICK. Following the guidance in this report will help you evaluate the impact of your work whether or not your organisation is a member of the PIF TICK.

Does your information make a difference?
To achieve the PIF TICK one of the questions you will need to address is 'Does your information make a difference?' (Criteria 10). Specifically, does your information address the information need you identified? Evaluating the impact of the work you do allows you to understand what works well and what might not be so effective. In the real world, sometimes your data will show you are not progressing in the way you hoped. It is just as important as evidence demonstrating progress.

This supports learning and improvement, and helps you to make sure that your funding, time, and resources are being used effectively.

Evaluation should consider equality and diversity issues and assess whether you are reaching the people who need the services you offer. Patients, carers, and those who use your service can see how you are working, and this can provide additional opportunities for collaboration.

> **Evaluating the impact of the work you do allows you to understand what works well and what might not be so effective.**

Evidence of impact can support fundraising activity by demonstrating the value of your work to your stakeholders or providing evidence that there are gaps in provision you need to address.

Evaluating impact does not have to involve complicated or expensive processes. There are lots of simple tools available, many of which are free to use. This guide will provide an overview to help you to plan your approach. It includes links to other sources of useful information and relevant tools – see section 6.

What we are covering

This guide covers how to approach evaluating the impact of health information. This includes individual health information resources, the use of health information resources through information and support services, or their use within a patient pathway. The principles are the same for all channels of communication (in person, paper, telephone, online, WhatsApp etc), but the tools you choose might be different.

This guide will not cover the evaluation of knowledge and library services, as comprehensive guidance is available from Health Education England. See more in the resources section.

Getting started

Start with a structured approach breaking down your project to define:

- What is the need or gap you are trying to address?
- What are you intending to do?
- What resources will you use?
- What would you like to achieve?
- How will you know whether it has worked?
- What metrics/feedback will help you to assess whether it has worked?
- How will you use that data to identify opportunities to improve?

This means you need to be thinking about how you will evaluate impact from the beginning of your project.

That does not mean you need to do everything at once. Your first step might be to find out whether you are reaching the people you planned to – your output. You might not move on to looking at outcomes and impact until you have achieved your aim in that first step.

What do we mean by evaluating impact?

It is important to be clear on terminology to avoid confusion. When we talk about evaluating impact we are trying to measure whether the work we have done has delivered the results we hoped to achieve. This takes your insight beyond understanding your outputs and outcomes – see definitions below.

Outputs – How many leaflets you sent out, how many sessions you ran, or how many videos you published.

Outcomes – What did people do as a result? Did the leaflet provide the information they needed or direct them to the right service?

Impact – Did people feel that they had the information needed? Did they feel able to make informed decisions?

Case study: Healthinote | Cognitant

healthinote.com

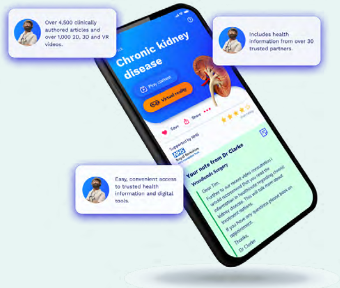
Healthinote hosts more than 5,000 pieces of health information in a variety of formats from trusted sources. Cognitant's visual health information, co-created with patients, is also available on the platform.

Clinicians can search Healthinote and send patients an information prescription via text, email or QR code. Healthinote is integrated with eConsult, used by almost 50% of GP practices in England and is used in some secondary care settings. Patients can use healthinote.com to search for health information themselves.

Output

» More than 3,000 GP practices in the UK have access to the Healthinote platform

» Around 5,000 Healthinote prescriptions are issued per month



Your note from Dr Clarke
Woodlands Surgery
Dear Tim,
Further to our recent video consultation I would recommend that you read the information in healthinote regarding chronic kidney disease. This will talk more about treatment options.
If you have any questions please book an appointment.
Thanks,
Dr Clarke

Outcomes

» >96% user satisfaction rating

» 10 minutes patient engagement per session

Impacts

» Up to 70% increase in knowledge of a topic after viewing a Healthinote prescription*

» Up to 35% intention to change behaviour after viewing a Healthinote prescription*

» Statistically significant increase in successful self-injection technique vs traditional training methods*

*relates to visual immersive content created by Cognitant and hosted on Healthinote

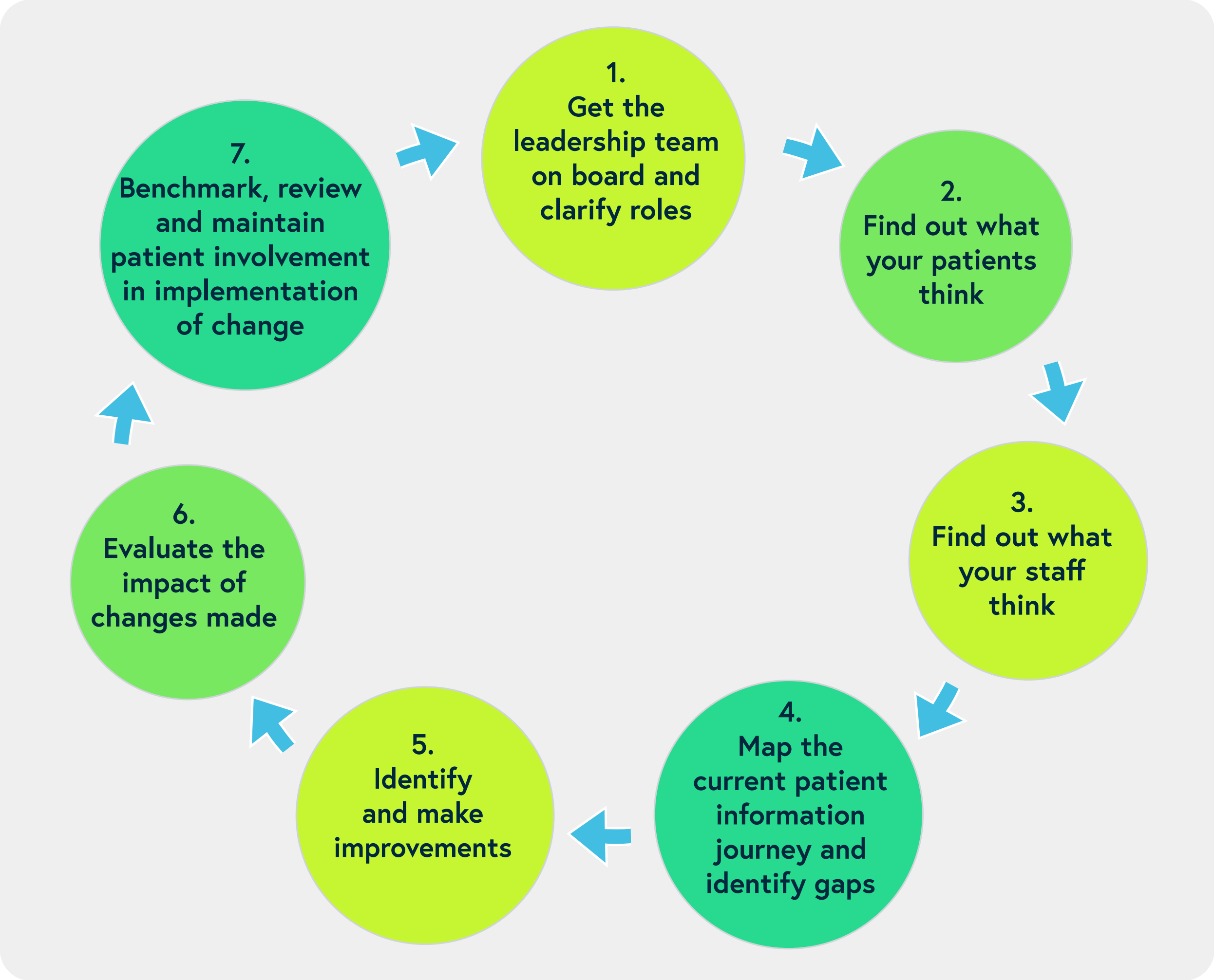
Where does this fit in the PPIJ and PIF TICK?

PPIJ and the PIF TICK

Evaluating impact is specifically highlighted when you reach step 6 in the PPIJ. At that stage you will be starting to look at your data, (see the detailed Perfect Patient Information Journey guidance).

However, you need to be planning from the beginning. When you are talking to your patients, staff and stakeholders and identifying the gaps in your current patient information journey, think about the changes you want to see as a result of the improvements you are planning.

This will help you identify what type of data you need to measure to evaluate whether you have been able to achieve the impact planned.



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

PIF TICK

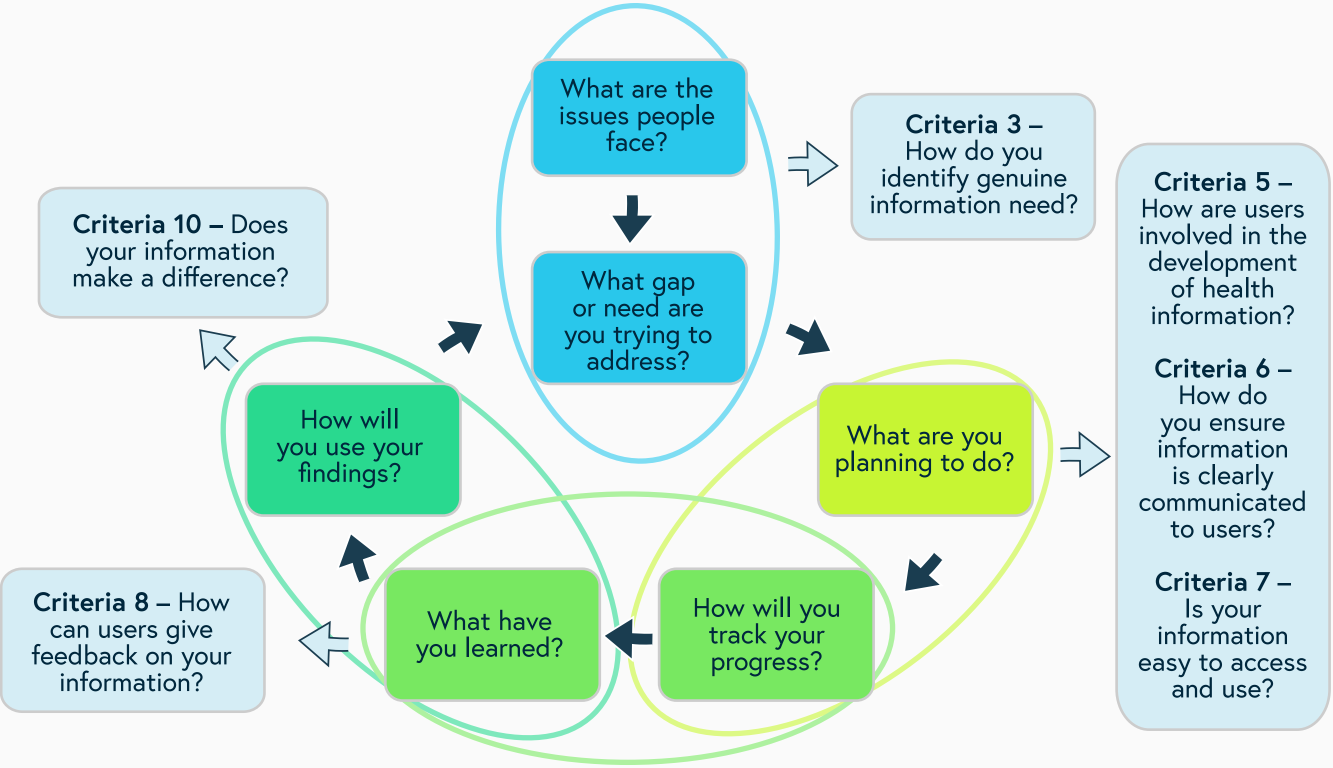
Trusted Information Creator

Members of the PIF TICK will know the final criteria (10) asks: 'Does your information make a difference?' How will your evaluation demonstrate the impact of your information? As you work through the PIF TICK criteria you will find the evidence you collate provides the framework to help you to meet that final criteria.

Criteria 3 – *How do you identify genuine information need?* covers the beginning of the process. Your resource proposal will provide an outline of the issues for your target audience, the evidence of the need gathered by working with those people, details of their health literacy needs, and any specific issues around accessibility that might be relevant for the proposal.

Once you are clear on the information need, think about what you are aiming to achieve.

PIF TICK and the evaluation cycle


What are the issues people face?

What gap or need are you trying to address?

Criteria 3 – How do you identify genuine information need?

Criteria 5 – How are users involved in the development of health information?

Criteria 6 – How do you ensure information is clearly communicated to users?

Criteria 7 – Is your information easy to access and use?

What are you planning to do?

How will you track your progress?

What have you learned?

How will you use your findings?

Criteria 8 – How can users give feedback on your information?

Criteria 10 – Does your information make a difference?

→ How will you know whether you have been successful? What data can you review to assess your progress?

Recording this at the beginning of the process in your design brief or project proposal will provide a baseline to work from and help you to explain your rationale.

As you work your way round the cycle each criterion contributes to the process, so you are gathering the evidence you require to complete that final step and demonstrate the impact of your information.

66% of PIF TICK members have started to identify ways to monitor the impact of health information since joining the scheme

Case study: The impact of video information | Guy's and St Thomas' NHS Foundation Trust

Guy's and St Thomas' NHS Foundation Trust was a founder member of the PIF TICK scheme. This brief case study describes the framework of evaluation of video content. The Trust is one of the first to employ a videographer. It uses video to meet the information needs of the diverse inner London population it serves.

The framework for evaluation

Criteria 3 – Identifying information needs

How is it of benefit to the target patients?
How is it of benefit to the organisation?
What need is being fulfilled by having this film?

Criteria 8 – How can users give feedback on your information

» Was the information well received?
» Feedback at launch and at 6 months
» Viewing analytics
» Patient feedback (verbal and written)

Criteria 9 – Does your information make a difference?

Reducing hospital attendance using instructional video

One video shows transplant patients how to take their own blood tests. The second demonstrates how to administer antibiotics via an IV drip. Both support patients to have the confidence to safely carry out these procedures at home. The videos have reduced hospital attendance.

Reducing anxiety with reassuring content

A film to reduce anxiety about cataract surgery aims to encourage patients not to delay or put off having surgery. The cataract video is sent via a link to patients. Viewing figures are well above average. The film is 2.31 mins long and average viewing time is 1.54 mins. 80% are still viewing at 2 mins. This implies the film is reaching the right audience and has a very good viewing retention.

Plan, Do, Study, Act (PDSA) Cycles

The PDSA cycle is recommended by NHS Improvement and is another model to describe the process of ongoing improvement.

Before you enter the improvement cycle you need to determine:

- What you are trying to accomplish
- How you will know that the change is an improvement
- What changes you want to implement to achieve that improvement.

There are then four stages to the PDSA cycle:

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.

NHS Improvement provides additional guidance.

Evaluation models

A challenge when evaluating the impact of health information is that projects are almost always part of a complex system.

This means, in most cases, you need to identify evidence to demonstrate that your work is contributing towards outcomes and impact, while acknowledging that other sources of treatment, information and support will also have contributed.

> **A challenge when evaluating the impact of health information is that projects are almost always part of a complex system.**

Measuring impacts for the system and patients

- You develop an information leaflet which provides information about how and when an individual can manage the symptoms of their condition, and the signs and symptoms that would usually suggest they might need to seek additional clinical support.
- The long-term impact you are hoping for is that people feel confident to manage their condition effectively and know when they need to seek support from their clinical team.
- One of the outcomes might be reduced emergency calls to the clinical team.
- You could ask a simple question to start to gather data to evaluate your progress such as:
  - 'If you didn't have this information what would you have done instead?'
  Either as an open question, or with a range of choices (e.g. called my GP, attended A&E, called my named nurse, tried to find information online).

Logic models

It can be helpful to use a tool such as a logic model to bring all of this into a visual format to help you to plan. A logic model aims to summarise your project and show the relationships between the inputs, activities, outputs, outcomes and impact.

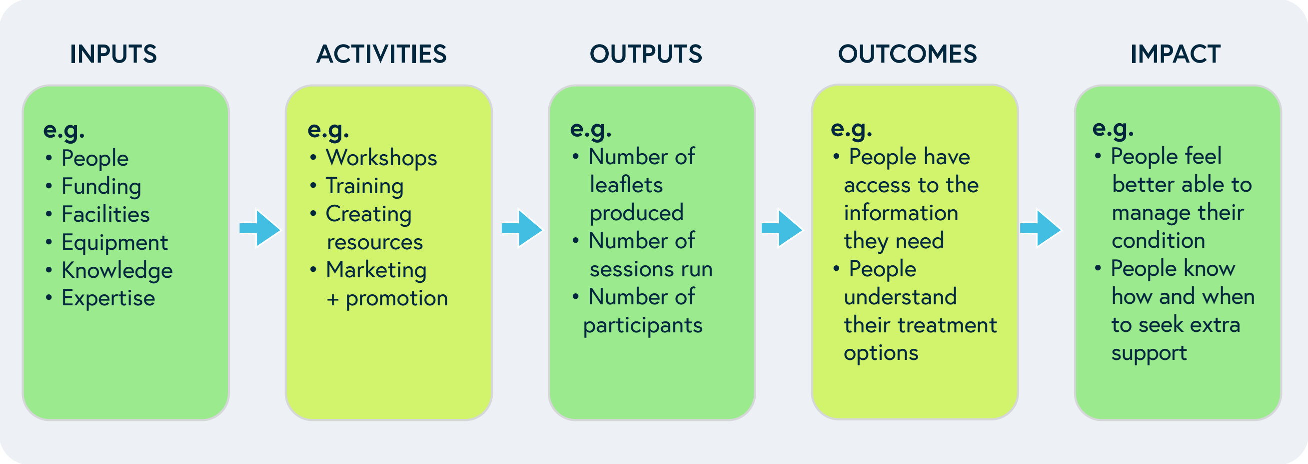
A logic model tends to be presented as a linear diagram – see right. It is also important to think about the evaluation of impact as a cycle – see next page.

All the learning you gather during the process can be used to help you make progress.

Using this type of cyclical approach, you can demonstrate what you have learnt so far – for example, how many people you have **reached**.

You can then work out how that data will inform the next stage in your evaluation as you work towards understanding whether you have delivered the **outcomes** and **impact** that you were hoping to deliver.

You can find further information about logic models and links to templates on the gov.uk website.



INPUTS	ACTIVITIES	OUTPUTS	OUTCOMES	IMPACT
e.g. • People • Funding • Facilities • Equipment • Knowledge • Expertise	**e.g.** • Workshops • Training • Creating resources • Marketing + promotion	**e.g.** • Number of leaflets produced • Number of sessions run • Number of participants	**e.g.** • People have access to the information they need • People understand their treatment options	**e.g.** • People feel better able to manage their condition • People know how and when to seek extra support

The logic model as a learning cycle

Adapted from NVCO learning cycle
knowhow.ncvo.org.uk/organisation/images/cycle.PNG/view

Case study: Activating digital citizens with health technologies | ORCHA

What are the issues people face?
People need to be signposted to trusted digital technologies.

What gap or need were you trying to address?
The people with greatest health needs are least likely to engage with digital technologies.

What did you do?
Advertised Healthier Lancashire and South Cumbria's digital health library on Facebook across the region with a focus on mental health, diabetes and asthma using trusted messengers.

How did you track your progress?
Click through from Facebook to download. Cost per click calculated by reduced burden on health service.

What have you learned?
Mental health campaign – Young men aged 16-21 had the highest level of engagement. Cost per click to download was 18p.

Diabetes – Women aged 35-55 had highest level of engagement – 74p per click. Service provision is well understood by patients who were better able to navigate to appropriate service already.

Asthma – Boys aged 13-16 had the highest engagement – cost per click was 23p. This demographic is most likely to present at hospital at point of crisis.

How will you use your findings?
- Refined our targeting with new messages
- Used learning to develop a social media campaign working with young people on mental health apps.

Theory of change

For larger or more complex projects a Theory of Change can be more helpful. The principles are still the same. A Logic Model is effectively a simple Theory of Change. Developing a robust Theory of Change can take longer, and ideally you will need to work with key stakeholders to develop it. Stakeholders might include patients or service users, carers, representatives from key partner organisations or key people from your organisation.

The advantage of a Theory of Change is it enables you to show the complexities of the factors contributing to change, and the relationships between them. New Philanthropy Capital (NPC) provides detailed step by step guidance and offers training and expert support if required. The National Council for Voluntary Organisations (NCVO) offers advice on software that can be used to help you create your theory of change.

Summary of Theory of Change in 10 steps (NPC)

1. **Situation analysis** – identification of the problem or issue, and what you can offer.
2. **Target groups** – who are the people or institutions you want to work with?
3. **Impact** – what is the sustained or long term change you would like to see?
4. **Outcomes** – what are the shorter-term changes for your target group that will contribute to impact?
5. **Activities** – what are you going to do?
6. **Change mechanisms** – how will your activities cause the outcomes you would like to see?
7. **Sequencing** – this stage aims to map out the order in which you think outcomes and impacts will be achieved.
8. **Theory of Change diagram** – NPC recommends trying to map all your information into a summary diagram.
9. **Stakeholders and 'enabling factors'** – what could stakeholders or organisations do that might affect your Theory of Change; what other factors might help or hinder you (for example political or environmental factors; personal circumstances affecting individuals)?
10. **Assumptions** – this is intended to help you to test your theory for any weaknesses or uncertainties.

PPIJ at St Mark's: Empowering patients with newly diagnosed inflammatory bowel disease

St Mark's IBD service has been the pilot site for PIF's Perfect Patient Information Journey project since 2017.

St Mark's pilot – Phase 1 – Mapping information need

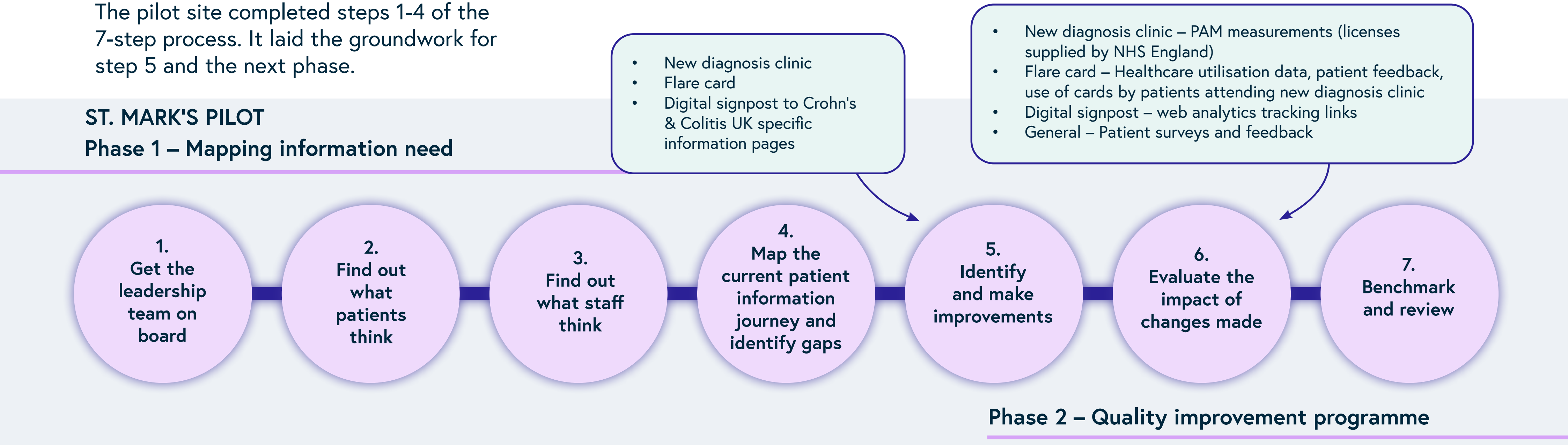
The recommendations of the first PPIJ report were tested at St Mark's Hospital. During the pilot a 7-step process was developed to implement the PPIJ in practice. The second PPIJ report detailed the work at St Mark's. The pilot site completed steps 1-4 of the 7-step process. It laid the groundwork for step 5 and the next phase.

St Mark's pilot – Phase 2 – the Quality Improvement Programme

The next phase of the project took the recommendations from insight work with patients and the IBD team and implemented them as part of a Quality Improvement Programme. The IBD team at St Mark's worked in partnership with PIF and Crohn's & Colitis UK to develop the programme. Impact measures were part of the design.

Collaborative working

NHS England supported the project with Patient Activation Measures (PAM) to measure the impact of a new diagnosis clinic. Crohn's & Colitis UK supplied content and bespoke tracking links to its information from a digital signpost created for St Mark's. PIF provided expert advice throughout the project cycle. AbbVie provided funding to support the project.



ST. MARK'S PILOT

Phase 1 – Mapping information need

- New diagnosis clinic
- Flare card
- Digital signpost to Crohn's & Colitis UK specific information pages

- New diagnosis clinic – PAM measurements (licenses supplied by NHS England)
- Flare card – Healthcare utilisation data, patient feedback, use of cards by patients attending new diagnosis clinic
- Digital signpost – web analytics tracking links
- General – Patient surveys and feedback

1. Get the leadership team on board
2. Find out what patients think
3. Find out what 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 and review

Phase 2 – Quality improvement programme

The impact of COVID-19

The COVID-19 pandemic started six months into the 12-month project. It changed the lives of patients and staff. The new diagnosis clinic was suspended for three months as staff resources were allocated to the COVID crisis. There were no routine endoscopies to diagnosis IBD in this period and it took time to re-establish the New Diagnosis of IBD Clinic (NDC) as a virtual clinic. Some patients with accessibility issues could no longer participate. A number of patients became ill and recovered, others lost their jobs, factors that could possibly influence their patient activation. One patient taking part in the project sadly died of COVID-19.

The flare card was available during the pandemic and was used by patients, but it is difficult to draw any conclusions from the healthcare utilisation data as this was disrupted by the crisis. Overall the information improvements implemented were judged a success by clinicians and patients.

CROHN'S & COLITIS UK

ST MARK'S HOSPITAL

Managing my Crohn's or Colitis flare-up

Flare-up

People with Crohn's disease and Ulcerative Colitis have times when they have few symptoms (remission) and times when symptoms flare-up (relapse). This leaflet explains what to do if you think your IBD symptoms have returned and who to contact for support. It is important to tackle a flare-up quickly to stop it getting out of control.

Contact the IBD Advice Line after taking the steps listed in this card. Telephone: 020 8235 4155 (Voicemail). If you think your symptoms are worse than those listed in this card please contact your local A&E Department or Urgent Care Centre.

Produced as part of the Patient Information Journey process by the Patient Information Forum. www.pifonline.org.uk.
AbbVie has provided funding for this project.

> **I felt well supported and advice and information was very customised to me specifically. Thank you.**
>
> – Patient

Importantly the NDC had a positive impact on PAM despite the pandemic. Good use was also made of the flare card and digital signpost (see logic model for results).

Benchmarking and next steps

The project highlighted new learning. A person's mental health issues impact their ability to improve their Patient Activation and manage their physical health conditions.

The initial move to an online clinic highlighted the needs of people with digital accessibility issues and those who required additional language support.

Thought had to be given to promote signposting to Crohn's & Colitis UK resources when people were not attending hospital clinics or lacked access to digital tools. These learnings are all part of the cycle of continuous improvement the PPIJ is designed to promote.

Patient surveys identified new priorities, including information to support shared decision-making, information on mental wellbeing and on conception, pregnancy and birth.

The project has also had wider impacts in terms of promoting the value of health information and its impact. It was included at a Parliamentary showcase in March 2019 and abstracts have been presented at European Crohn's and Colitis Organisation 2020 conference, United European Gastroenterology Week 2021, and at the St Mark's Hospital Grand Round. www.stmarksdigital.com/education/grands/lovesh-dyall-patient-empowerment-in-ibd.

The reflections of the St Mark's team on the process follow the logic model on page 19.

> **Patients' needs are complex and evolve with the broader health landscape. The quest for best care is an infinite journey.**
>
> – Dr. Naila Arebi

St Mark's digital signpost

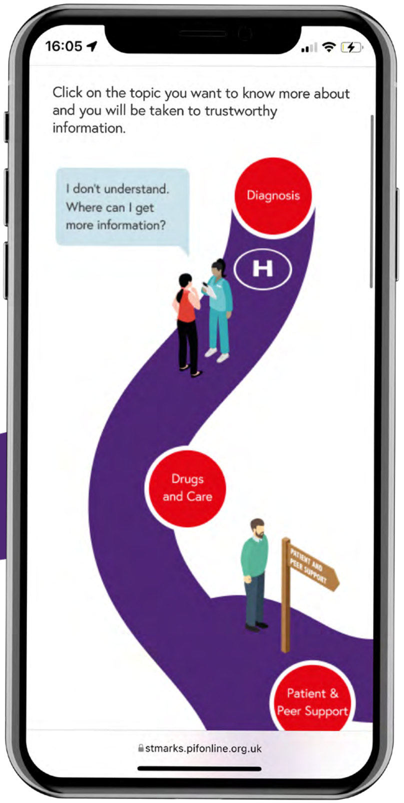
stmarks.pifonline.org.uk

The first phase the St Mark's pilot found relatively low awareness among patients of the information and support provided by Crohn's & Colitis UK. The interactive patient journey was developed in response and links areas of information need identified by St Mark's patients to pages on the charity's website.

Patients at the NDC made good use of the signpost. The most used areas were drug therapy and surgery. New educational resources could be directed at these two key aspects of IBD care to support shared decision-making.

See logic model on page 19 for detailed results.

> **I now have this on in the background and often patients will point to one area during the clinic that they would like to focus on. This makes it easier to signpost the right information.**
>
> – Dr. Lovesh Dyall


16:05

Click on the topic you want to know more about and you will be taken to trustworthy information.

Logic model

Rationale

Tailor improvements to meet key patient needs identified during PIF's Perfect Patient Information Journey workshops and patient surveys.

To ensure compliance with IBD standards by empowering patients' knowledge and confidence in managing their IBD.

Provide condition specific-information and the signposting of patients to verified sources of information which is part of standard care according to the IBD standards.

Improve access to good quality and relevant patient information at diagnosis to improve patient skills, knowledge and confidence in self-management.

Work in partnership with PIF and national charities to avoid duplication of resources and improve signposting to quality resources.

Use Patient Activation Measures, a validated tool, to evaluate the effect of information.

Activities

A New Diagnosis of IBD clinic (NDC) was set-up. Patients had a 45-minute consultation with an IBD physician and nurse specialist. The topics included general information on IBD, triggers to relapse, self-management of mild relapses and signposting to reliable information sources. (Face to face during pandemic, virtual from March 2020.)

Use of Patient Activation Measures to track changes in patient activation levels. PAM is a 13-question tool, which generates a score from 1 (poor activation) to 4 (high activation). A patient with a PAM score of ≥3 is considered 'activated'. St Mark's IBD Patient Information booklet updated to provide clearer information and signposting.

Flare Card developed in partnership with Crohn's and Colitis UK and PIF to help patients self manage the early signs of flare and make appropriate use of services. Reviewed by St Mark's multidisciplinary team.

A digital information pathway to signpost patients to the trusted information provided by Crohn's & Colitis UK and specific services at St Mark's Services. The pathway matched patient identified points in the information journey where information and support was required.

Inputs

Establishment of Quality Improvement programme at St Mark's with multidisciplinary team support.

Supply of Patient Activation Licenses and support in their use from NHS England.

Update of St Mark's IBD Booklet.

Project support from PIF included:

- Development of flare card, based on material in development by Crohn's & Colitis UK Scotland.
- Development of a digital information pathway to signpost patients to trusted sources of information.

Outputs

PAM scores were taken prior to NDC (T1), immediately following NDC (T2) and 12 months later (T3). The primary outcome was the proportion of activated patients at 12 months. The secondary outcome was the proportion of patients exhibiting an increase in PAM score by ≥1.

Data on age, gender, ethnicity, smoking, IBD sub-type, and baseline disease activity were collected.

At T3, the participants were asked to self-report the number of times calls were made to the hospital IBD advice line, use of the flare card, access to the Crohn's and Colitis UK page, and use of steroids (either oral or intravenous) and admission to hospital.

We also examined the use of a novel IBD interactive patient journey chart and measured the dwell time – time spent on a web page for a reader to go through the material, as a marker for engagement.

An amendment to assess patient activation was made in response to the COVID-19 pandemic. Additional information relating to change in employment due to COVID-19, and/or having PCR proven COVID-19, and the use of healthcare resources was collected. Median (IQR) and mean (±SD) described continuous variables.

Outcomes

Primary

- Improve quality of care in patient-centred domain.
- Demonstrate improvement in patient activation through the use of information interventions.
- Monitor patterns in healthcare utilisation by patients with different activation levels.

Secondary

- Empower patients to manage their disease.
- Standardise the process of sharing disease information with patients.
- Signpost patients to specific and relevant information resources.
- Reduce IBD knowledge gaps when these are identified.

Impact

The project started in September 2019 and was scheduled to run for 12 months. The COVID-19 pandemic had a major impact on the project. The NDC was put on hold for three months and changed from a face-to-face appointment to a virtual setting.

New diagnosis clinic

54 patients attended the new diagnosis clinic (NDC); 38 completed the study (20 male). The 16 lost to follow-up (LFU) only had a baseline score recorded and were excluded from 12 month analysis.

Median age was 42 (range 18-83) years. 24 patients had ulcerative colitis, 10 Crohn's disease, and 4 had IBD-unclassified. 25 had active disease at baseline. The mean time from symptom onset to NDC attendance was 3.26 (±2.89) months.

At T1, the median PAM score for the 38 patients was 3 (IQR 2) in contrast to 1 (IQR 1) for the LFU group. There were more activated (PAM score ≥3) than non-activated (PAM <3) patients at T1: 63% (24) and 37% (14) respectively. At 12-months (T3), 23/38 (60%) had a PAM score ≥3; 11/38(29%) had an improvement in PAM of ≥1 and 13/38 (34%) patients had no change.

Improvements in PAM scores for the inactivated group were important to assess the impact of the NDC interaction, increased PAM by ≥1 was noted for 8/14 (57%) at T2, (p=0.0133) and 9/14 patients (64%) at T3. PAM score changes were independent of disease activity, age, gender, ethnicity or smoking. Figure 1 (page 21) demonstrates the Sankey chart for the change in PAM scores between T1, and T3.

At 12-months, none of the non-activated patients were admitted to hospital, compared with one activated who was admitted to hospital, and showed a high use of healthcare resources (eight calls made to the hospital IBD advice line, referred to the Flare Card twice, had two courses of steroids, and called the Crohn's & Colitis UK helpline twice).

Information use

Use of the IBD advice line and CCUK webpage at 12-months was higher for the activated group (28 calls made) compared to the non-activated cohort (22 calls); this was associated with lower steroid use (2 courses of steroids activated, compared to 10 in the non-activated group) although this result was not statistically significant (p-value= 0.24604).

During the COVID-19 pandemic, consultations were conducted remotely by telephone or video-call. Our novel IBD interactive patient journey chart was used 170 times. At 12 months, the average dwell time on pages was 2 minutes 5 seconds, more than double the industry average. The most visited pages were treatment and surgery.

COVID-19 cases

Six patients reported PCR positive COVID-19 infection (1 death) and 9/38 patients reported a change in employment due to COVID-19. The COVID-19 affected group, 5/15 patients had a PAM score ≤2 at T1; an improvement in PAM by ≥1 was seen at T3 in all 5 cases. 6/9 (67%) activated patients in the COVID-19 group at T1 maintained activation at T3. 19/24 patients in the non-COVID-19 group made use of healthcare resources compared to 8/14 in the COVID-19 group (p=0.0027).

Discussion by Dr Lovesh Dyall
The objective of this quality improvement study was to examine changes in patient empowerment following structured patient education within a dedicated NDC using PAM scores as a measure.

However, the majority of our patients were highly activated before the intervention (63% with PAM score >3). This left a smaller number (37%) to examine for improvement at T2 immediately after clinic and at 12 months.

Nevertheless at 12 months, activation for the whole cohort was sustained and from the non-activated cohort at baseline, 57% and 64% showed improvement in PAM score >1 at T2 and T3 respectively. See the sankey chart to the right.

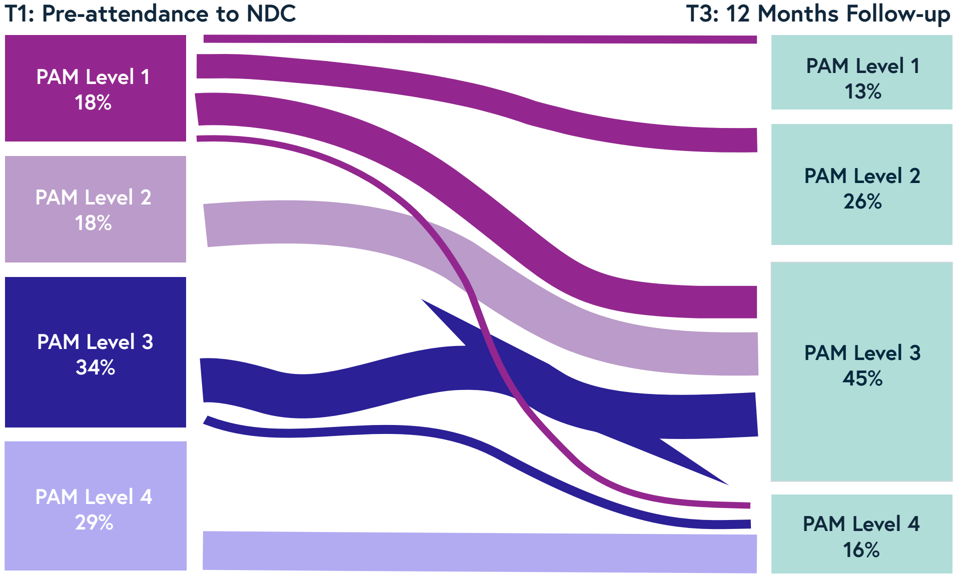
The reasons for the high proportion of activated patients at baseline are unclear. It may reflect the educational level of our local population, or a delay between diagnosis and attendance at the clinic allowing time for self-education.

We did not find a correlation between age, gender, ethnicity and PAM scores and increase in PAM scores between activated and inactivated groups. There were no significant differences in healthcare utilisation between activated and non-activated patients.

> **PAM at diagnosis may offer a measurable way to identify non-activated patients who may benefit from more intensive support.**

Use of PAM
PAM at diagnosis may offer a measurable way to identify non-activated patients who may benefit from more intensive support. Patients lost to follow-up showed a lower median PAM score. Non-activated patients at baseline showed an increase in PAM score.

Non-activated patients may benefit from closer IBD specialist nurse support to reduce risk of non-compliance with follow-up appointments and offer additional support during periods of relapse.



Sankey chart of baseline PAM Level at T1 and flow over time to T3 (12 months follow up). A higher proportion of patients were activated at T3 compared to T1. Percentages rounded to highest number. The thickness of the line correlates with the number of patients: the thicker the line the more patients.

Conversely highly activated patients may be directed towards a more patient directed follow-up and self-management.

An appetite for information

In our cohort, highly activated patients accessed the IBD advice line, and Crohn's and Colitis UK helpline, yet this did not correlate with an increased use of steroids, suggesting that there was an appetite for self-directed information.

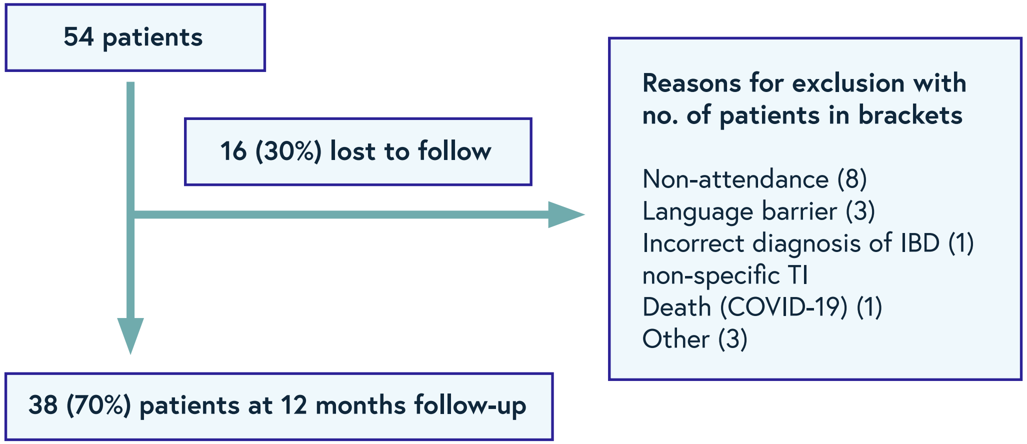
The overall benefit of such a strategy may translate into healthcare cost gains: a single increase by 1 of PAM level has been shown to be associated with a decrease by 8.3% of follow-up healthcare costs.

Conclusion

Patient activation at baseline was sustained at 12 months. There was an improvement in PAM of ≥1 immediately after attendance at the NDC.

This improvement is independent of the patient demographics, or disease status. The COVID-19 pandemic was not associated with a worsening in PAM, or an increase in demand on healthcare resources. The patients lost to follow-up had a lower PAM score. PAM can be used to triage patients who may not engage with therapy.

We would like to see PAM being given before each clinic attendance for two purposes: for the clinician to recognise which aspects of care they would need to focus on during the consultation and for the patient to see their journey (ideally with improving PAM).



54 patients

16 (30%) lost to follow

38 (70%) patients at 12 months follow-up

Reasons for exclusion with no. of patients in brackets

Non-attendance (8)
Language barrier (3)
Incorrect diagnosis of IBD (1)
non-specific TI
Death (COVID-19) (1)
Other (3)

Patient flow chart with patient numbers (percentages in bracket) at baseline and 12 months follow-up.

> **Conversely highly activated patients may be directed towards a more patient directed follow-up and self-management.**

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1. Hibbard JHG, H. Supporting people to manage their health: An introduction to patient activation. The King's Fund 2004
2. Barnes EL, Long MD, Kappelman MD, Martin CF, Sandler RS. High Patient Activation Is Associated With Remission in Patients With Inflammatory Bowel Disease. Inflamm Bowel Dis. 2019;25(7):1248-54
3. Lindsay A, Hibbard JH, Boothroyd DB, Glaseroff A, Asch SM. Patient Activation Changes as a Potential Signal for Changes in Health Care Costs: Cohort Study of US High-Cost Patients. J Gen Intern Med. 2018;33(12):2106-12

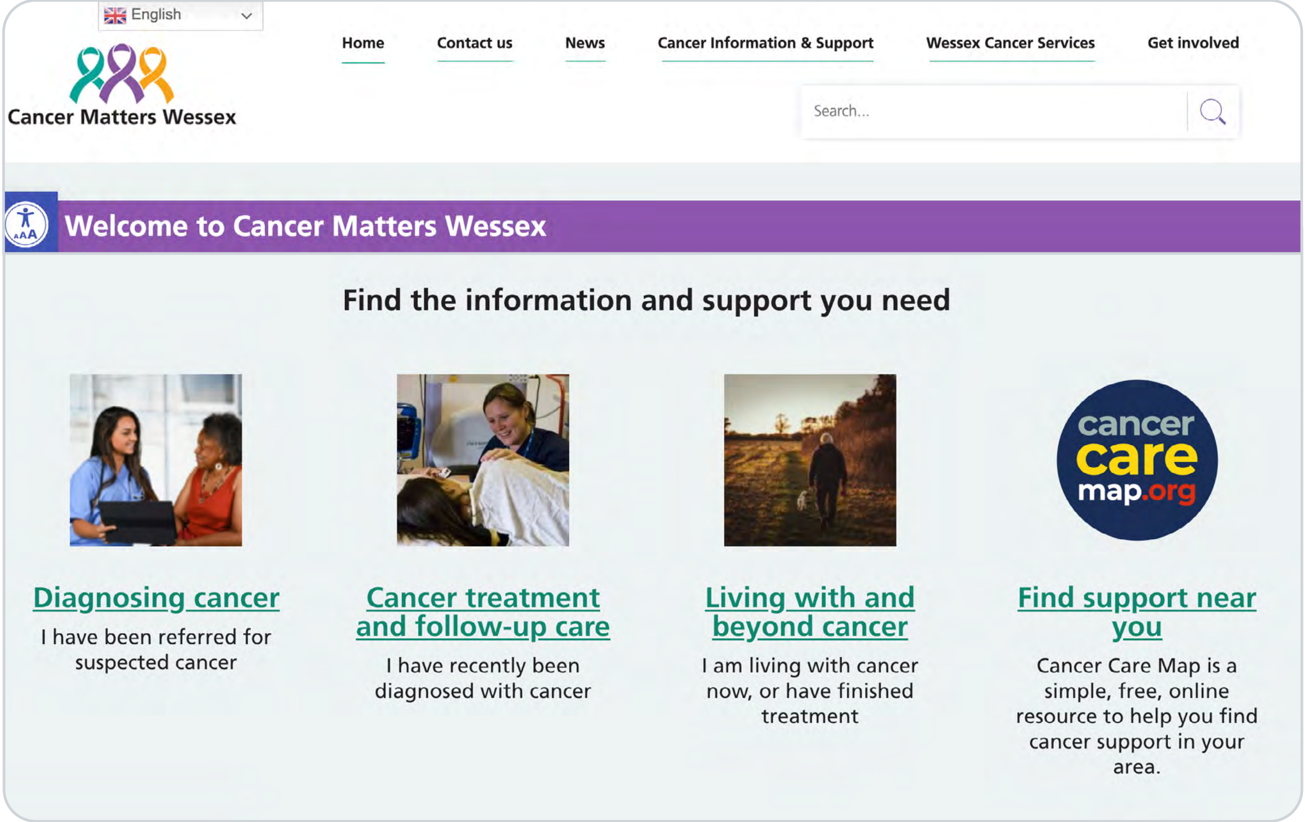
Cancer Matters Wessex

The aim of the Dorset Macmillan Cancer Information Project (DMCI) is to ensure cancer patients, families and carers can access information, support and signposting via the Cancer Matters Wessex website.

PIF provided initial support for the project, which mapped information needs using the PPIJ process. This is reflected in the structure of the website. PIF also advised on measures to evaluate the impact of the project.

The project works across the whole county, so an integrated approach to working across health and social care and the voluntary and community sector is essential.

DMCI mapped out their approach using a logic model to enable them to define the project approach in detail and show how they planned to achieve short and medium term outcomes and impact.



Welcome to Cancer Matters Wessex

Find the information and support you need

Diagnosing cancer
I have been referred for suspected cancer

Cancer treatment and follow-up care
I have recently been diagnosed with cancer

Living with and beyond cancer
I am living with cancer now, or have finished treatment

Find support near you
Cancer Care Map is a simple, free, online resource to help you find cancer support in your area.

Next steps are to utilise the networks to continue engagement and user involvement in cancer services, to promote patient and public involvement with wider networks at Wessex Cancer Alliance.

Logic model

Rationale

Ensure that cancer patients, their families and carers across Dorset can access information, user support and sign posting.

Provide various ways for people to take up opportunities for guidance and sign-posting.

Break down barriers through partnership working and integration across health and social care and the voluntary and community sector, providing a Dorset and system-wide approach to cancer information and signposting provision.

Inputs

Management/Staff
Facilities: IT infrastructure, Internet, IT hardware and software, access to virtual platforms

Partnerships with primary and secondary care

Volunteers and community networks

Financial costs
Sponsorship from Macmillan Cancer support for posts

Funding from Macmillan non-standard grant

Activities

Core:
Information Broadcasts
with volunteers,
with nonclinical workforce in primary care,
with other groups

Outreach and awareness raising

Support groups

Partnership working influencing and supporting local activity

Development of Cancer Matters Wessex content

Outputs

Website analytics demonstrate:
Increase in visits to CMW

Directory of Services
Increase in links to Cancer Care Map Directory

Healthcare professionals
Signpost to CMW

National Cancer Patients Experience Survey

Outcomes

Short term
People affected by cancer:

- feel they can access the information they need at a particular point in time
- have increased knowledge of the different services available
- have increased understanding of their personal situation and how to access support
- experience increased confidence
- feel less confused
- experience less anxiety/stress
- carers have a better understanding of the support available to them

Medium – Long-term
People affected by cancer:

- can access other services
- can make good decisions
- have increased sense of control, choice and empowerment
- are more able to self-manage

Impacts

People living in Dorset who are living with or affected by cancer will:

- be treated with dignity and respect
- enjoy life
- understand and so make good decisions
- know what they can do to help themselves and who else can help them
- feel part of a community and inspired to give something back
- get the treatment and care that is best for their cancer and life
- feel that those around them are well supported

Online screening tool for Raynaud's phenomena

Scleroderma & Raynaud's UK (SRUK) is dedicated to improving the lives of people with scleroderma and Raynaud's phenomena (RP). It aims to improve awareness and understanding of these conditions, to support those affected, fund ground-breaking research and ultimately, to find a cure.

Based on research data the team identified evidence of unmet information needs. 1 in 2 people are not aware of the symptoms of Raynaud's phenomena.

Scleroderma symptoms

Up to 95% of people with scleroderma experience Raynaud's as their first symptom. A person can live with Raynaud's for up to 5 years or longer before they show signs of other non-RP symptoms which could indicate scleroderma.

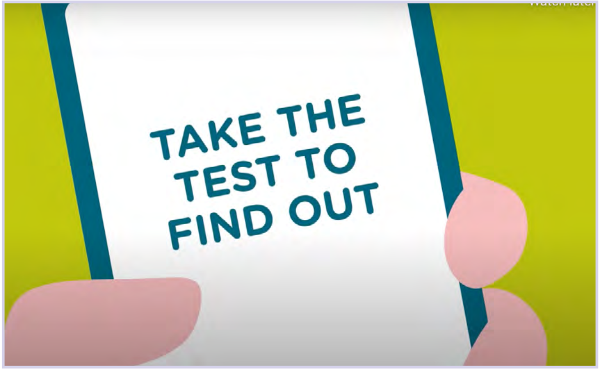
145,000 people have taken the online test since 2018

However, 25% of women were not diagnosed with scleroderma until ten years after the emergence of Raynaud's symptoms.

The team developed an online screening test for Raynaud's in collaboration with experts. The questions were derived from existing Raynaud's phenomena validated classification criteria.

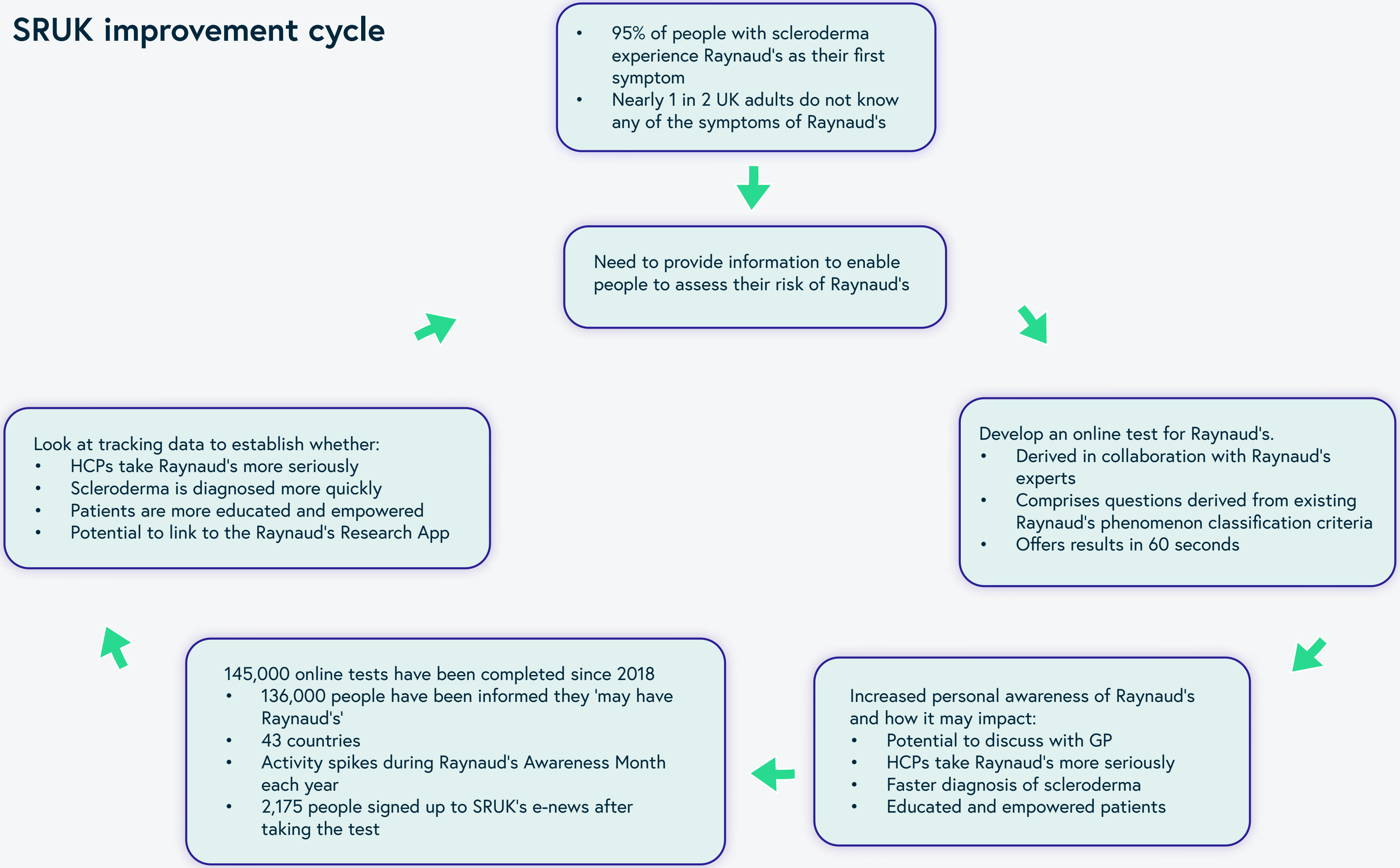
The online test offers results in 60 seconds. It aims to increase personal awareness and identify those people who may have Raynaud's empowering them to seek medical advice where appropriate.

SRUK wanted to evaluate the impact of its screening tool, so it began by looking at tracking data. 145,000 people have taken the online test since 2018.



sruk.co.uk/raynauds/raynauds-test

SRUK improvement cycle



- 95% of people with scleroderma experience Raynaud's as their first symptom
- Nearly 1 in 2 UK adults do not know any of the symptoms of Raynaud's

Need to provide information to enable people to assess their risk of Raynaud's

Develop an online test for Raynaud's.
- Derived in collaboration with Raynaud's experts
- Comprises questions derived from existing Raynaud's phenomenon classification criteria
- Offers results in 60 seconds

Increased personal awareness of Raynaud's and how it may impact:
- Potential to discuss with GP
- HCPs take Raynaud's more seriously
- Faster diagnosis of scleroderma
- Educated and empowered patients

145,000 online tests have been completed since 2018
- 136,000 people have been informed they 'may have Raynaud's'
- 43 countries
- Activity spikes during Raynaud's Awareness Month each year
- 2,175 people signed up to SRUK's e-news after taking the test

Look at tracking data to establish whether:
- HCPs take Raynaud's more seriously
- Scleroderma is diagnosed more quickly
- Patients are more educated and empowered
- Potential to link to the Raynaud's Research App

Encouraging people with lung cancer symptoms to return to care

The Do It For Yourself (DIFY) campaign is a collaborative project between Roy Castle Lung Foundation, Mesothelioma UK, Macmillan Cancer Support, UK Lung Cancer Coalition, Lung Cancer Nursing UK and 9 NHS Cancer Alliances in two bursts in 2020 and 2021. It was funded by MSD.

The aim was to help address the impact COVID-19 has had on people presenting with possible lung cancer symptoms.

The campaign encouraged people to contact their GP if they had experienced a continuous cough and/or ongoing breathlessness for three weeks or more. Focus groups with the target audience were used to test behavioural drivers and campaign artwork.

> **The team deliberately selected some of the most socially challenged and deprived areas to deploy the DIFY campaign.**

The campaign ran during the pandemic so the team had to work with the NHS to ensure that patients could be safely directed back to their GPs without overburdening the system.

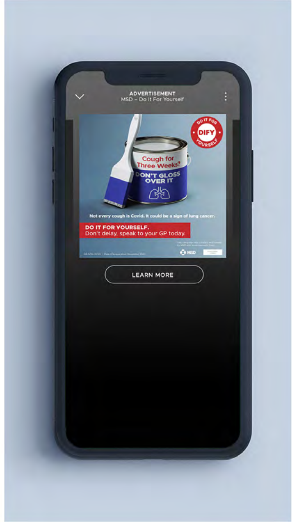
The first phase took place with Northern and Greater Manchester Cancer Alliances. It took place during full lockdown and focused on advertising on transport, essential retail locations and on radio to capture key worker and retired audiences.

The second phase was expanded to the eight Cancer Alliance regions as society began to unlock. The range of materials was expanded for use by local community support workers and included leaflets and pop-up banners for mass vaccination centres.

Targeting inequality

The team deliberately selected some of the most socially challenged and deprived areas to deploy the DIFY campaign. These areas were worst hit by delayed lung cancer presentation and slowest to recover.

70% of Cancer Alliances indicated the campaign positively impacted their local populations.

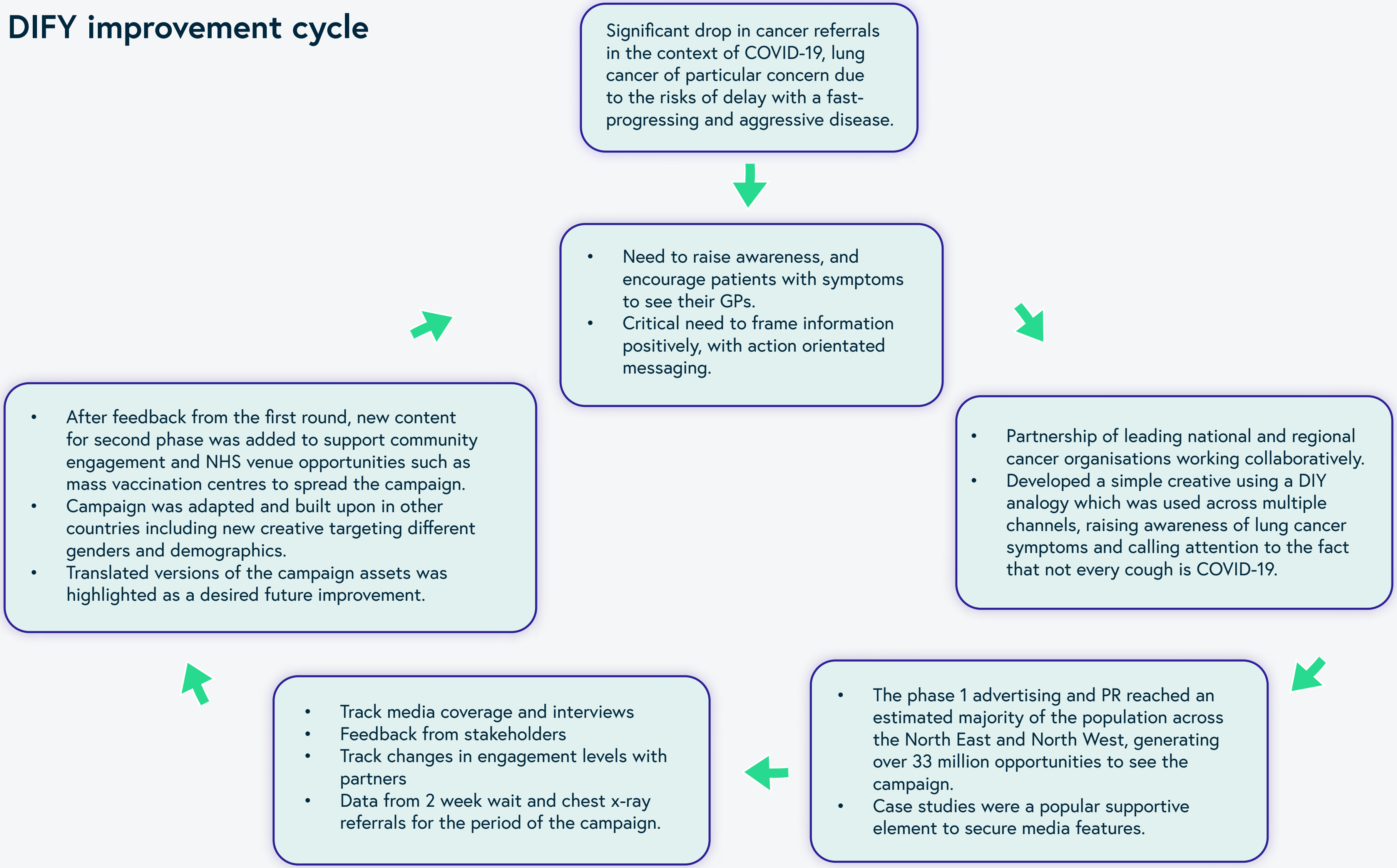


The improvement cycle (see next page) summarises the initial approach. In addition the team have now been able to identify some evidence to demonstrate the impact of the campaign:

- 70% of Cancer Alliances indicated the campaign positively impacted their local populations.
- The statistics on return to care are very variable across England. However, the team have observed during the months the DIFY campaign ran and immediately after there was a 5.4% increase in suspected lung cancer referrals compared to previous months.
- In the regions where the campaign did not run there was an observed reduction in referrals of 2.5%.

An evaluation of the campaign is available here.

DIFY improvement cycle



Significant drop in cancer referrals in the context of COVID-19, lung cancer of particular concern due to the risks of delay with a fast-progressing and aggressive disease.

- Need to raise awareness, and encourage patients with symptoms to see their GPs.
- Critical need to frame information positively, with action orientated messaging.

- Partnership of leading national and regional cancer organisations working collaboratively.
- Developed a simple creative using a DIY analogy which was used across multiple channels, raising awareness of lung cancer symptoms and calling attention to the fact that not every cough is COVID-19.

- The phase 1 advertising and PR reached an estimated majority of the population across the North East and North West, generating over 33 million opportunities to see the campaign.
- Case studies were a popular supportive element to secure media features.

- Track media coverage and interviews
- Feedback from stakeholders
- Track changes in engagement levels with partners
- Data from 2 week wait and chest x-ray referrals for the period of the campaign.

- After feedback from the first round, new content for second phase was added to support community engagement and NHS venue opportunities such as mass vaccination centres to spread the campaign.
- Campaign was adapted and built upon in other countries including new creative targeting different genders and demographics.
- Translated versions of the campaign assets was highlighted as a desired future improvement.

Impact tools

There are lots of ways to gather evidence and new tools are developed all the time. It's important to choose the right tools for your project. This section will provide a short introduction to some methods you might want to consider using, along with details of where to find additional support and guidance.

Plan your budget

Many tools are freely available, but some do involve costs so you will need to factor that into your decision-making process. It is important to think about how you will analyse and use the information you collect. You need to consider the capacity and/or expertise available to do the analysis. If you cannot analyse the data it will not add the value you are looking for.

Try to plan the time and resources for each stage of your work so you can gain some real insight and learning from the process.

Many of the tools available can be used through different channels, online, on paper, via telephone or in person. Your choices will be influenced by how you are delivering your information or your service.

Choose the right tools

If your information is being delivered through a website, you are most likely to be looking at tools that can be used online. You might want to use a survey to test the effectiveness of the work you have done to improve the visibility of your information through Search Engine Optimisation (SEO). This could provide evidence of your ability to reach the people who need it.

An online focus group could help you gather feedback about your online community and identify if it is meeting people's needs.

Always think carefully about your key questions, as different channels for feedback can offer new or different insights.

Defining reach

Before looking at more in depth impact tools it is important to evaluate your outputs and their reach. How you define reach is dependent on the context. Essentially, it is about attempting to quantify your service offer and who is accessing it.

If, for example, you are developing a leaflet your reach could include:

- Number of organisations ordering/downloading copies
- Number of individuals ordering/downloading copies.

If you are offering a service you might have a different set of options such as:

- Amount of people visiting the service
- Whether they are patients, family members, carers, friends or healthcare professionals
- Where service users come from – both geographical area and referral pathway
- Personal demographics.

If you have created a new web page you can include:

- Number of visitors to the page, including how many are new visitors
- Dwell time – the amount of time people spend on a page
- Geographic location of users
- Demographic information, for example, gender.

Some of this information will be automatically collected by your organisation, some is available via surveys or website analytics tools. If you are designing a survey or web form you can ask demographic questions to see who you are interacting with. This might include, for example, age, ethnicity, gender and education.

The more information you have the more you can stratify into different user groups. Breaking down your reach into user groups provides more rich and interesting data and highlights potential gaps in your reach.

Once you have established the reach of your outputs you can start to assess the impact they may have overall and for specific groups.

Types of evaluation

There are two main types of evaluation. Both types of data are valuable and will provide different types of insight.

Quantitative – numerical or statistical information which can be gathered and analysed. For example, healthcare utilisation data including surveys with closed questions, A&E statistics and emergency admissions.

Qualitative – more detailed descriptive feedback including experiences and opinions. For example, user surveys with open ended questions and patient interviews.

There can be challenges with the analysis of both types of data.

Quantitative data analysis might require statistical support for detailed data sub-analysis.

Qualitative data is great for rich feedback and it can also be analysed to extract themes and insights. However, those doing the analysis must be aware their conscious and unconscious biases have the potential to influence their analysis.

There are services available to support the objective analysis of qualitative data, but these do usually involve some costs (see resources section for examples).

Starting your process with a clear outline of what success will look like helps you to choose the most appropriate methods to assess your progress. Frequently a mixture of quantitative and qualitative approaches will be needed.

Impact tools

The following pages cover impact tools:

- ➜ Surveys
- ➜ Validated questionnaires
- ➜ Interviews
- ➜ Focus groups
- ➜ Complaints and compliments
- ➜ User stories/case studies
- ➜ Outcomes Star

Surveys

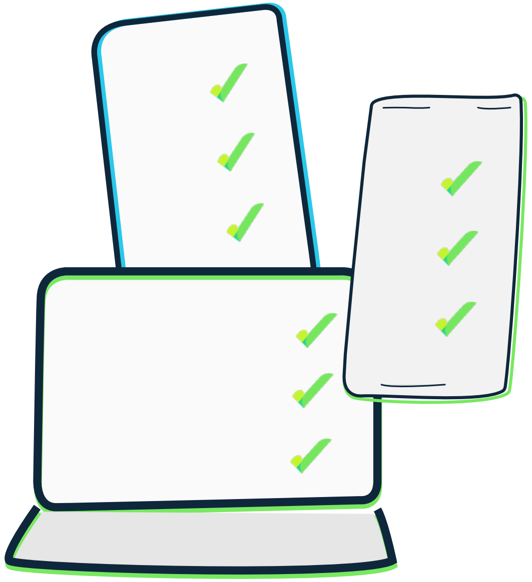
Predominantly used to collect quantitative data, but qualitative questions can be included.

Pros	Cons
Relatively easy to set up	Questions need to be prepared carefully to avoid influencing the answers
Can choose to use one or more channels and keep the survey consistent	It may result in a lot of data to analyse
Some online tools will analyse some of the information for you	Paper-based surveys will require manual processing
Can be cheap and easy to use	Some questionnaires can only be used under licence so there can be costs involved

Surveys are a common tool for gathering feedback. They can be used in a variety of ways, online, on paper, or through asking questions in person, or provided to people to complete in their own time. You can use a survey over a limited time to gather feedback for a specific purpose, you can run them periodically to track progress, or you can use them on an ongoing basis to track feedback over time.

You can collect both quantitative and qualitative data through surveys, but you should always think carefully about the questions you want to ask. You are asking people to give up their time to provide feedback, so make sure you are only collecting information that you need and intend to use.

You should also think carefully about how you word your questions, so you do not inadvertently influence the responses.



Top tips

- Make sure you use plain language.
- Aim for a reading age between 9-11.
- Test your questionnaire with a small group of volunteers before you start using it.
- This provides an opportunity to check people understand your questions, and to ensure you have addressed any accessibility issues.

There are broadly two categories of question:

- **Closed questions** – providing two or more options to choose from
- **Open questions** – allowing people to answer in their own words

Open questions will provide qualitative data and offer detailed insights into the experiences of those responding. However, answering an open question can take much longer than just choosing a response from a list, so they should be used with care.

Analysing this type of feedback can be time-consuming, and it can be difficult to draw firm conclusions or compare your findings over time.

Be careful to think through how you will use the data you receive and what you will use this data for, and ideally with, the people who respond.

Note that some funders, such as pharmaceutical companies, may require you to report on Adverse Events identified through survey work. This can be time-consuming and resource intensive, as adverse events have to be reported within 24 hours.

Additional guidance is available from NCVO and NHS England.

If you want to run your survey online there are lots of organisations offering free platforms. The Charity Catalogue offers a list of potential options.

If you are using an online platform make sure you have a data protection statement and make it clear if you are collecting unique identifiers like IP and email addresses.

Validated questionnaires

There are validated questionnaires available that can be used to evaluate your work. Some, like Patient Activation Measures, are not specific to disease area and measure people's skills and confidence. If you are working with clinical colleagues there are other health-related quality of life scores that can be helpful.

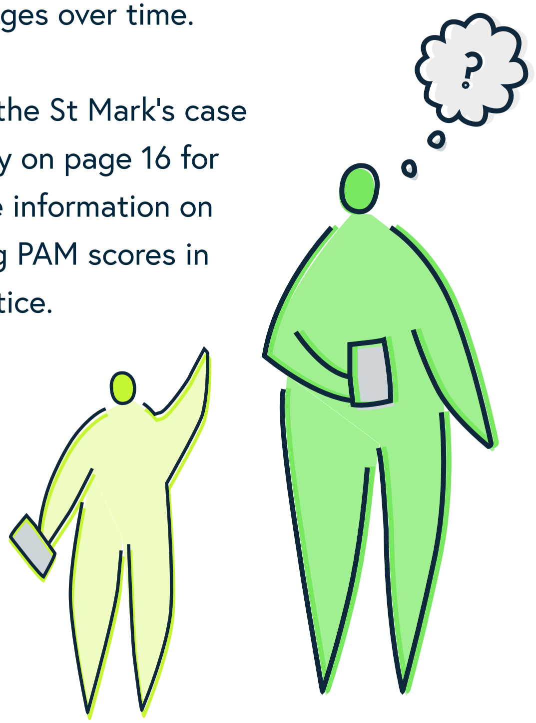
Patient Reported Outcome Measures (PROMs) are questionnaires used in some areas of the NHS to gather feedback from patients about their experience of care. They are usually designed to gather feedback on specific patient pathways but they do offer a standardised set of evidence-based questions for those pathways. You can find additional information from NHS England, Health Improvement Scotland, and NHS Wales.

Patient Activation Measures (PAM®): The PAM® is a validated questionnaire licensed from Insignia Healthcare LLC. NHS England has made licences available to a range of NHS organisations, but licensing is also available direct. The questionnaire consists of 13 questions, and respondents are matched to one of four 'activation levels' based on their responses. See diagram on the next page.

The tool aims to measure people's knowledge, skills, and confidence in managing their own care and well-being – their 'patient activation'. This can be helpful when you are looking to evaluate your impact, as it provides an evidence-based measure which can be used periodically to demonstrate whether your intervention has facilitated change by improving the level of 'patient activation'.

Ideally the questionnaire should be used before your intervention to establish a 'baseline' level of activation. It should be repeated after the intervention, or at intervals during the period of intervention, to evidence whether the level of activation changes over time.

See the St Mark's case study on page 16 for more information on using PAM scores in practice.



PAM: INCREASING LEVEL OF ACTIVATION

Level 1	Level 2	Level 3	Level 4
Disengaged and overwhelmed.	Becoming aware, but still struggling.	Taking action.	Maintaining behaviours and pushing further.
Individuals are passive and lack confidence. Knowledge is low, goal orientation is weak and adherence is poor.	Individuals have some knowledge, but large gaps remain. They believe health is largely out of their control, but can set simple goals.	Individuals have the key facts and are building self-management skills. They strive for best practice behaviours, and are goal orientated.	Individuals have adopted new behaviours, but may struggle in times of stress or change. Maintaining a healthy lifestyle is a key focus.
Their perspective: 'my doctor is in charge of my health'.	Their perspective: 'I could be doing more'.	Their perspective: 'I am part of my health care team'.	Their perspective: 'I am my own advocate'.

england.nhs.uk/wp-content/uploads/2018/04/patient-activation-measure-quick-guide.pdf

Interviews

Generally used to collect qualitative data, but quantitative questions can be included.

Pros	Cons
Rich insight into individual experiences	Time-consuming to analyse
Accessible for people who might find other formats challenging	Ideally you need a skilled interviewer
Flexibility to use different channels	Individual experiences may not be relevant to others

Interviews offer an opportunity to gain insight on a one-to-one basis. They can take place in person, via the telephone, or online via social media platforms or video conferencing facilities.

Interviews can be structured, with pre-planned open and/or closed questions. If you choose to use this approach you are effectively using an in-person survey, and all the same issues and planning considerations will apply.

The alternative is an unstructured interview where you are led by the interviewee and they can choose what they would like to talk about to give feedback on your impact. This is effectively an open question, but as the question itself is very broad it provides an opportunity for people to highlight issues that are important for them. This can provide great insight and high-quality experiential data. It can also identify issues you may not have been aware of.

Interviews can be very time-consuming, it can be challenging to analyse the data, and some of the feedback you receive may not be directly relevant.

For example, the interview might provide the opportunity for someone to explain challenges that lie outside your remit.

Interviews: Key points

- Think about whether the interview will take place online or in person, and whether that affects any of your planning.
- The interviewer should have a clear understanding of the questions they need to ask, and how far you would like them to probe for any additional insights.
- The interviewer should have skills and experience in conducting interviews and be aware of any additional communication requirements.
- If either the interviewee or the interviewer needs additional support this needs to be in place ready for the interview, e.g. personal assistant, facilities to accommodate a guide dog or wheelchair, BSL or language interpreter.
- The interviewer will need to explain how the interview will be run, what you will be doing with the data, and ensure that they have obtained and recorded the consent of the interviewee. This may also include adverse event reporting if funded by a pharmaceutical company.
- Ensure you have support available to follow up if any critical issues are raised and/or if either the interviewee or the interviewer become distressed as a result of the conversation.
- Plan a suitable location for the interview, ensuring it offers a safe, confidential space, and is accessible for anyone attending in person.
- How will you record the feedback? Think about whether the interviewer will take notes, or you will record it so that it can be transcribed later and obtain consent for the recording.

Focus groups

Generally used to collect qualitative data.

Pros	Cons
Rich discussion drawing on multiple perspectives	Requires skilled facilitation
Participants may contribute more as the discussion develops within the group	Can be time-consuming to analyse

A focus group brings together a group of participants with a facilitator to guide the discussion. A second facilitator is needed to take notes and offer practical support with the organisation and management of the session.

The facilitators will come with a clear discussion guide, including key questions and topics to be covered during the session, and will encourage all participants to contribute. The interactions between individuals in the group offer an additional opportunity for insight, as they can stimulate discussion and debate.

In the context of evaluating your impact you are most likely to be looking for a group of people who have used your information or your service. They will already have some shared characteristics.

Top tip

In general, focus groups should involve between 6 and 10 participants. If the group is too small there is limited opportunity for discussion and debate. If too large, quieter participants find it difficult to contribute.

People with similar backgrounds and experiences are more likely to relax and contribute openly.

You may want to plan two or more groups to involve a broad range of people. Focus groups can run in person or online, but in either case they tend to be 45-90 minutes long, and they need to be planned carefully with skilled facilitators.

Focus groups: Key points

- Think about whether your focus group is running in person or online, and what additional options you might want to use when facilitating the group e.g. flipcharts, pens and post-it notes in person; polls, shared whiteboards and chat functions online.
- Plan a suitable location ensuring it offers a safe, comfortable space and is accessible for anyone attending in person.
- Ensure you are aware of any additional support needs, and plan ahead to accommodate them e.g. personal assistant, facilities to accommodate a guide dog or wheelchair, BSL or language interpreter.
- The purpose of the focus group, and the expectations for participants should be clearly explained in advance, including how the discussions will be recorded and analysed and what you will do with the insights you obtain.
- A confidentiality agreement for the group is particularly important, as participants may disclose personal information during the discussion.
- The facilitators should obtain and record the consent of all participants.
- During the introduction to the focus group the facilitators should reiterate the purpose of the group, set out the ground rules for the discussion, and explain their roles.
- The facilitators should bring a clear discussion guide and have the skills to steer the discussion through the planned questions within the time available. They will also need to ensure participants are encouraged to engage and made to feel comfortable.
- The facilitators should be able to respond to the discussion in a non-judgemental way and ensure everyone is able to contribute.
- Ensure you have support available to follow up if any critical issues are raised and/or if a participant becomes distressed as a result of the discussion.

Key points continued on the next page

- At the end of the session the facilitators should draw the discussion to a close, provide any key feedback to the group and explain what they will be doing next.
- The facilitator should explain how they will use the insights from the group, and how they will communicate their findings.

Additional guidance is available from NCVO, including guidance on how to run a focus group.

Complaints and compliments

Generally used to collect qualitative data.

Pros	Cons
You should already collect this data	Some complaints and compliments may be specific to one individual experience
You can use your recorded actions to demonstrate that you are implementing improvements	Data tends to be submitted by people who have had particularly good, or particularly bad experiences

As a team you should have processes in place to record and respond to any feedback you receive, whether that is positive or negative, and what actions you took because of it.

This data can also be helpful as a collated set over time. Analysis can offer an opportunity to identify trends or themes over defined periods of time. This form of engagement can open opportunities to work more closely with people who have direct experience of your offer, if they are prepared to share their contact details.

If you are looking at data from this dataset you should always bear in mind that people are most likely to provide feedback if they have had a particularly difficult, or particularly good experience. This should be taken into consideration when examining any trends or themes that emerge. Sharing information about the actions you have taken, changes you have made, and what you have learned from feedback with your stakeholders can offer great opportunities for engagement.

User stories/case studies

Generally used to collect qualitative data.

Pros	Cons
Rich and detailed insights	Analysis can be time-consuming
Powerful communication tools	Stories can be very personal, and experiences may not be replicated for others

User stories and case studies can offer rich, detailed insights and can also be very powerful communication tools. There are many ways to approach them depending on the skills and capacity of your team, and the people you are working with.

- Some people will be happy to write about their experience, or draw a picture to illustrate it.
- Some people will be happy to tell their story to someone, and check that it has been recorded accurately.
- Some people may need significant support to explain their experiences, through an advocate, carer, or friend.

Analysing the feedback you receive through this method can be time-consuming, as each person will have their own individual experiences. This is both a strength and a weakness of this option. You can identify some helpful insights which you could explore further using other methods if necessary.

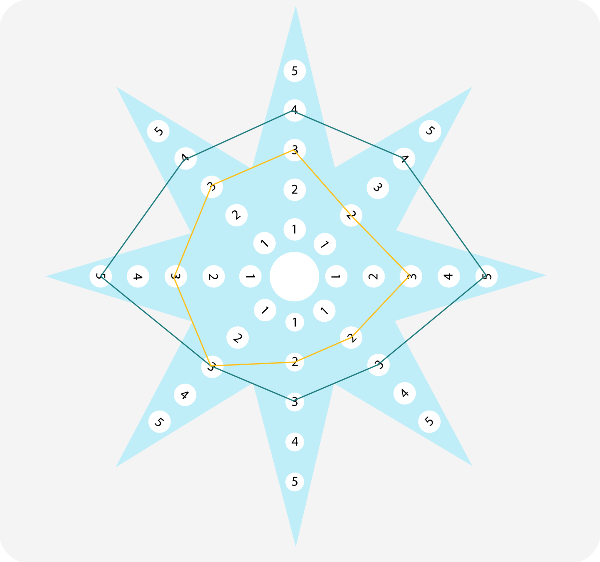
Individual stories can be a fantastic way to bring your data to life when you are looking at how to share what you have learnt about your impact.

Outcomes Star

The Outcomes Star is a set of simple evidence-based tools designed to measure and support change when working with people. Outcomes Stars are designed to be used with individuals. They offer a simple visual format in the form of a star with each point displaying a set of scales covering key outcome measures relevant to the sector.

By choosing a level on each point of the star at key intervals an individual can record their experiences over time. This information can be used within supportive conversations and can also be analysed to demonstrate change over time and the impact of the intervention.

Outcomes Star™



There are a range of Outcomes Stars available (more than 30 to date) suitable for a variety of sectors, and training is available on how to use them effectively. They are only available under licence, so there are costs associated with their use.

Further information can be found on the Outcome Star website which also publishes a short briefing.

Creative options

When you are thinking about collecting data do not be afraid to be creative. Working with children? There's no reason why you cannot gather data about how they are feeling by asking them to draw a picture rather than trying to conduct an in-depth interview. You can find lots of information and inspiring case studies in PIF's Guide to Producing Health Information for Children and Young People.

Consider simple options such as a pair of jam jars labelled 'yes' and 'no' and a bowl of marbles – or the online equivalent – with a simple question above such as 'Were we able to offer the support or information you needed today? Please place a marble in the most appropriate jar'. This can help you start to gather relevant data about your service.

Summary and further guidance

Summary

Evaluating impact should be an integral element of your work. Setting out with a clear outline of what you would like to achieve, and how you will know if you have been successful will enable you to identify the data you will need to collect to measure your progress.

You should always be mindful that your conscious and unconscious biases, and those of your team and stakeholders, can influence your approach. Open and honest communications and broad engagement will help you to plan as effectively as possible.

In the real world, sometimes your data will show you are not progressing in the way that you hoped, and this is just as important as evidence demonstrating progress. Going back to review your plans with your key stakeholders with all the new information you have (whether positive or negative) can provide additional insights into ways to improve your impact. That ongoing learning cycle will ensure quality improvement is an integral part of the way that you work.

The learning you gain from evaluating your impact has many applications, and the way you communicate your learning will need to be tailored to each purpose. Some audiences will like to see numbers and graphs, and others will find individual stories and insights far more engaging. Think about what you are trying to communicate each time and try to pull out the information in a way that will resonate with the people you are working with.

> **That ongoing learning cycle will ensure quality improvement is an integral part of the way that you work.**

Feedback

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, you can either go to the PIF website, pifonline.org.uk, and complete the feedback form there or contact the PIF administrator admin@pifonline.org.uk with your comments.

Further guidance

Organisations that offer more help, training and/or guidance

Better Evaluation – offers free tools to help you identify suitable methods for your evaluation, along with guidance on each stage of the process including communicating impact.

The Health Foundation – focuses on improving health and healthcare in the UK. It has five key strategic priorities:

- Promoting healthy lives for all
- Data analytics for better health
- Supporting health care improvement
- Making health and care services more sustainable
- Improving national health and care policy.

As part of its work, it supports the Q Community, to foster continuous and sustainable improvement in health and care. There are currently more than 4,000 members from diverse backgrounds including those at the frontline of health and social care, patient leaders, managers, researchers, commissioners, and policy makers.

The community supports collaboration, the sharing of expertise, and access to development opportunities including events and training. There is an application process for membership, which is open to anyone with improvement expertise based in the UK and Ireland. Membership is free.

Health Improvement Scotland – the iHub provides access to resources, and examples of improvement and evaluation projects. The site is set up to support projects in Scotland, but the information can be used by anyone.

National Council for Voluntary Organisations – offers advice and support for voluntary organisations, including resources, advice, top tips, and online training courses.

National Voices – coalition of health and social care charities in England, with a particular focus on supporting person-centred approaches. Access to reports and publications, and a peer support hub.

NESTA – supports innovation for social good with three specific missions: a fairer start for every child; a healthy life for all, and a sustainable future where the economy works better for people and the planet. It offers access to a range of reports and runs events. Many past online events can be accessed from the archive.

New Philanthropy Capital (NPC) and Inspiring Impact – NPC offers a range of free tools and resources, along with additional paid options for training and consultancy support. It is a lead partner on Inspiring Impact, which offers free online resources, learning events and grant funding to help charities improve how they plan, deliver, assess and review their services.

NHS England and Improvement – offers a range of quality improvement tools, methods and approaches.

Wales Measuring What Matters – this online tool (or downloadable pdf toolkit) is designed to help you think through how to choose the appropriate tool(s) to measure impact within the context of your project. It guides you through thinking about the people your activity supports, the purpose of your evaluation, and the process involved.

Based on your choices, the tool will summarise your answers and then provide suggestions for potential tools and links to further information for each of those options.

WhatWorks – There are currently nine independent What Works Centres, three affiliate and two associate members aimed at supporting more effective and efficient services across the public sector at local and national levels and sharing the best available evidence. They help to ensure robust evidence shapes decision-making at every level and are useful as a source of evidence and data. Relevant centres include:

- National Institute for Health and Care Excellence (NICE)
- Centre for Better Ageing
- What Works Centre for Well-being
- Centre for Homelessness Impact
- What Works for Children's Social Care.

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Join us

PIF is the independent UK membership body for people working in health information and support. We operate the PIF TICK, the UK-wide quality mark for health information.

Our vision

Everyone has access to personalised health information and support to enable them to make informed decisions about their health, wellbeing and care.

Our Partners

abpi
ATC Association of Translation Companies
Bupa
Cancer Research UK
HIFA.org
Macmillan Cancer Support
MSD
National Voices
NICE National Institute for Health and Care Excellence
Norgine
Novartis
Pfizer
PRSB Professional Record Standards Body
Self Care Forum
texthelp

Published by the Patient Information Forum February 2022
Review date: February 2024

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