Patient Information Forum

Perfect Patient Information Journey: Phase 1 Summary Report

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

Contents

The Patient Information Forum

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.

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.

Patient Information Forum

For everyone involved in health information and support

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

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in patientinformationforum

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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

All web links in this document were accessed between November 2016 and March 2017.

Executive Summary

Background

Despite widespread belief in the importance of ensuring access to information, and despite strong evidence of its impact, people with long-term conditions still often face barriers to accessing high quality[1] information. Services are often still ill-equipped to properly inform patients throughout the pathway, meaning that they are less activated, less able to share in decision making related to their care, and less equipped to self-manage.

The project

To address this, PIF has launched the 'Perfect Patient Information Journey' (PPIJ) project, which aims to:

▸ Identify good practice principles to ensure the provision of high quality information for people with long-term conditions;

▸ Develop resources aimed at supporting patients, healthcare professionals and commissioners to better access, provide and commission high quality information;

▸ Pilot and evaluate these resources in a clinical setting.

The first phase of the project involved conducting research on previous efforts to embed information into patient pathways, as well as engaging with patients, healthcare professionals and commissioners in order to identify key themes related to the provision of high quality information.

Ten key points were identified:

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. It's obvious, but 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.

[1] PIF defines 'high quality information' as being information that is evidence-based, clearly-communicated, accessible, developed with users, and that meets the needs of individual users.

Key recommendations & next steps

Based upon the themes and good practice principles identified, PIF has developed a series of recommendations for stakeholders with a responsibility for improving access to information:

Commissioners

▸ Commission high quality information resources and services for people living with long-term conditions.

▸ Ensure services and staff are aware of their obligations to provide high quality health information to people living with long-term conditions.

▸ CCGs to appoint one member of their governing body to lead on the provision of high quality information within commissioned services.

Health services

▸ Ensure provision of high quality information is a key objective of all multi-disciplinary teams with responsibility for overseeing long-term conditions services.

▸ Appoint 'information champions' within services.

▸ Map the pathway contact points where information either is or could be provided, and ensure that responsibilities for providing information at these contact points are confirmed.

▸ Ensure provision of high quality information is a key development objective contained within personal development plans for all relevant staff, and that the importance of health information (and shared-decision making more broadly) is incorporated into existing training and education sessions.

Healthcare professionals

▸ Ensure awareness of key responsibilities related to the provision of information.

▸ Ensure awareness of high quality sources of information, and utilise these sources when signposting patients, including within consultations and care plans.

▸ Ensure that access to information is a key objective contained within all personal development plans.

▸ Co-design and co-produce, alongside patients, information packs and other resources to provide to newly-diagnosed patients.

▸ Participate in the development of shared decision-making tools.

▸ Ensure patients' information needs and requirements are monitored throughout the patient pathway.

Next steps for PIF

▸ Develop a Patient Information Commissioning Toolkit to raise awareness of the evidence and policy drivers that support the commissioning of high quality information.

▸ Develop a series of resources to support health services measure and improve how they provide information to service users, informed by the principles outlined in this report.

▸ Deliver a pilot of the resources, and evaluate the impact to service users and the service in improving the provision of health information.

Introduction

Providing care for people living with (often multiple) long-term conditions is one of the most critical challenges facing the NHS over the coming years.

With more than 15 million people currently living with at least one long-term condition in England[2], health policy has become ever more focused on improving health outcomes and reducing costs by making a reality of concepts such as 'self-management', 'shared decision-making' and 'patient activation'.

NHS England's Five Year Forward View, for example, speaks of how 'long-term conditions are now a central task of the NHS' and of how 'caring for these needs requires a partnership with patients over the long-term rather than providing single, unconnected 'episodes' of care.'[3]

A key component in this move towards greater personalisation of care is ensuring access to high quality information[4] for people with long-term conditions, and embedding it within care pathways so that it becomes an integral component of all interactions between patients and the health and social care professionals they engage with.

Yet, despite acceptance in the health and care community about the importance of access to information, there still exists substantial variation in the quality and consistency of information available to people with long-term conditions. Inequality of access to information for people living with long-term conditions is a reality, with access often being dependent upon geography, type of long-term condition, and individual circumstances.

Services are also often still ill-equipped to properly inform patients as they move through the patient pathway, meaning that individuals' abilities to self-manage and share decision-making is restricted.

A survey commissioned by PIF and MHP Health in 2015 among people with long-term conditions, for example, found that 36% of people interviewed disagreed that they were given helpful information when first diagnosed, while 32% reported finding it difficult to access trustworthy information on their condition.[5]

Indeed, in failing to provide patients with all the information and support they need to maintain their own health and to actively participate in decisions about their healthcare, the health service is currently compromising all three key dimensions of quality care – patient experience, patient safety and clinical effectiveness.

To address this issue, PIF has launched a project aimed at mapping out the 'Perfect Patient Information Journey' for people with long-term conditions.

This report represents the culmination of the first phase of the project, with PIF seeking to define good practice in relation to information access for people living with long-term conditions, by conducting research into examples of good practice and holding focus groups, interviews and a workshop with people living with long-term conditions, as well as healthcare professionals, commissioners, and representatives from patient organisations.

In so doing, PIF has identified a number of good practice principles which, if replicated across different pathways, can ensure equality of access to high quality information for people living with long-term conditions.

This report provides an overview of some of these key principles, which have been drawn both from the perspectives of patients and professionals, as well as lessons learned from case study research.

In addition to outlining these key principles, it also makes a number of recommendations aimed at ensuring access to information is embedded within long-term condition patient pathways.

These recommendations will be further developed in Phase 2 of the Perfect Patient Information Journey project, with a range of resources being produced by PIF that incorporate the good practice principles outlined in this report.

These resources will be implemented in a clinical setting to measure the impact that appropriate information provision, made available at the appropriate junctures, can have on people living with long-term conditions, as well as how this changes the experiences and attitudes towards information provision on the part of healthcare professionals and commissioners.

If you would like to keep in touch with PIF's ongoing work in this area, and find out more about the tools we develop and our project evaluation, you can join our mailing list by emailing neil.cowan@pifonline.org.uk.

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

[3] NHS, 'Five Year Forward View', October 2015, p.16. Available at https://www.england.nhs.uk/ourwork/futurenhs/

[4] PIF works to a wide definition of health information. It includes information about health services, the content that supports a person to understand and make decisions about their health, wellbeing, treatment and care, and patient related data such as health records and test results. High quality means health information that is accurate, reliable, clearly communicated, accessible, relevant, evaluated and developed with users. You can find out more about our best practice standards on the PIF website: https://www.pifonline.org.uk/pif-resources/best-practice/

[5] Patient Information Forum & MHP Health (2015), 'Is knowledge power?' Available at www.pifonline.org.uk/wp-content/uploads/2015/03/Is-knowledge-power.-Using-information-and-support-to-empower-patients..pdf

Summary of focus groups and interviews

Background

On 25 September 2016, PIF held two focus groups looking at access to information for people with long-term conditions. The first focus group involved people living with a range of long-term conditions (including multiple sclerosis, rheumatoid arthritis, fibromyalgia, chronic kidney disease, chronic heart failure and Alzheimer's disease)[6], while the second involved healthcare professionals and commissioners.

Following these focus groups, PIF staged a workshop at the National Voices conference of 25 January 2017, as well as an Open Space event on 26 January 2017; both of which brought together patients, healthcare professionals and patient organisations and focused on challenges and solutions in accessing and providing information.

Alongside these events, PIF has also undertaken 26 individual semi-structured interviews with people with long-term conditions, healthcare professionals and commissioners[7] to obtain their perspectives on the same issues.

Key themes

While focus groups, workshops and interviews alone cannot provide a complete picture on current patient information provision within the NHS for people with long-term conditions, some clear themes emerged from the discussions, which predominated regardless of the nature of the long-term condition or the specific role of the healthcare professional or commissioner.

An overview of these key themes, and the discussions from which they emerged, can therefore be presented. They include:

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[6] A limitation of the Focus Groups was that there was no direct representation of the voice of carers.

[7] 'Commissioners' were regarded to be individuals involved in the planning and commissioning of health services utilised by people with long-term conditions.

1. Information on first diagnosis is essential

For a sizeable number of patient participants, a repeated concern was the lack of appropriate information provided to them upon first diagnosis. For many patients, the issue was the total absence of information provided.

'When I was diagnosed, the consultant drew me a diagram of my brain, showed me what MS did to it, and that was that. For me, this was the point at which I really needed reassurance and a better understanding of what was going to happen to me, and I didn't get it.'

Some spoke of being told they had a long-term condition and, from their perspective, subsequently being left on their own to access the information they needed to make the decisions they were required to take about their care, as well as to come to terms with their diagnosis.

Others spoke of how they were provided with information, but that this information was entirely inappropriate for them, for example it was age-inappropriate, or used language that was either too simplistic or too clinical and complex.

Given the often-seismic upheaval, worry and confusion caused by a long-term condition diagnosis, it was clear that information could play a vital role in easing some of the initial fear involved, as well as allow for a better understanding of the potential impact of diagnosis on people's lives.

2. Information on first diagnosis can also be overwhelming

While information upon first diagnosis was considered vital by all focus group participants and interviewees, and was recognised by healthcare professionals as being important, it was also clear that the beginning of the patient pathway is not always the ideal point at which to either impart or comprehend all information.

'When I was first diagnosed, it was such a shock that I couldn't take anything in. I felt like I wanted to have all the information there possibly was but, looking back, I didn't comprehend any of it because of the trauma of the diagnosis. It took me months to get to the position where I was able to begin to better inform myself.'

Even in cases where an official diagnosis did not come as a surprise to the patient, the emotional turmoil that often results from diagnosis is such that it can often be an unsuitable time to provide individuals with the array of information that they need to play an active role in their care. Instead a sequenced approach may be required, dependent upon the individual needs of the patient.

Healthcare professionals, and particularly nurses, highlighted the difficulties they can often face when seeking to support patients upon first diagnosis. While aware of the fact that they needed to provide the right type of information to patients at this crucial period, they stated that this was often difficult due to the emotional impact of diagnosis on patients.

'My ideal would be, when you first diagnose someone, you give them a number that they can call. Denial is a big part of diagnosis, and people are different in terms of how long this denial lasts. I find that when that denial is over, that's when they need to talk and get the information they need. It isn't straight away.'

Even when information (whether made available verbally or written) was provided, healthcare professionals were concerned that this information was not always understood by patients and that it would often take weeks, or even months, for patients to accept their diagnosis and be sufficiently informed to allow them to begin to play an active role in their care.

3. Information needs change as people move along the pathway

It was clear that participants, as they move along the patient pathway and better understand their condition, require different levels of information. One participant spoke of how living with and getting to know a long-term condition was like studying a language:

'At first you feel a bit lost and confused, but you eventually learn the basics, then you get a bit better, then you end up fluent. Information about my condition is the same; at first I needed the basics but I'm now pretty much an expert and so the information I needed 5 years ago, isn't the same information I need now.'

Several participants reflected this, and described how they now considered themselves to be experts in their condition. However, many felt that the information provision they needed to allow them to take an active role in their care had not kept pace with their own development, and that there were difficulties for them in accessing the 'expert' information they needed.

Importantly, there were also clear examples of good practice cited. One participant, living with chronic kidney disease, described how being able to access PatientView (an online platform which allows renal patients to view their test results, clinic letters, and information about diagnosis and treatment) had played a significant role in allowing him to play an active role in his care, and to feel like an 'equal partner' with his consultant.

'The patient I was 10 years ago, or even 1 year ago, is very different to who I am today. My relationship with my consultant and the nurses has changed, but sometimes the information that's available to me hasn't really evolved alongside that.'

Access to this information has allowed the patient to utilise the expert knowledge they have obtained about their condition, and to truly work in partnership with the healthcare professionals involved in their care.[8]

[8] For more information on accessing personal health records, see PIF's 'Personal Health Records: Learning from voices of experience', which can be read here http://www.pifonline.org.uk/wp-content/uploads/2017/01/PiF-PHR-Guide-2017-V2.pdf

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

Each patient is an individual, and each patient journey is distinct, however it was clear from all participants that there are definite points along each patient's journey at which access to information becomes of even greater importance.

> 'When there's changes in care or a deterioration in my disease I need new information. When these changes happen, or additional conditions come on, that's when you need new information.'

One such example is upon first diagnosis, but other key points include when there is any change or, particularly, deterioration in the condition.

Patient participants spoke of wanting to be provided with information in advance, where possible, when a deterioration in their condition might occur, e.g. people living with MS highlighted their desire to know about the possible progression of their condition in advance of this progression occurring, rather than as it occurs.

Another key stage in the pathway repeatedly cited was any point at which a decision had to be made related to changes in treatment or care, for example a decision over whether to be initiated on to a new course of treatment.

> 'I was asked to choose between two new courses of treatment, but I was just given their drug names, a one page leaflet and that was that. I needed more but I didn't really get it, so in the end I just chose one.'

While some patient participants reported positive experiences in such scenarios, others reported being provided with little or no information when asked to decide between courses of treatment.

Again, participants spoke of the importance of being provided with information ahead of the point at which the decision needed to be made.

5. It's obvious, but information must be tailored to the needs of the individual

> 'I'm of working age, but my condition usually affects people who are much, much older. The information I've been given has been totally useless to me. I need to know about the impact on my ability to work and bring up my family, but I haven't ever really been provided with that and it's been left to me to find out.'

It was apparent that the information being provided to people with long-term conditions can often be inappropriate or unsuited to the individual, whether because of its age-inappropriateness, the level of expertise at which it is pitched, or the type of condition the individual is living with.

Many spoke of their perception that a 'one size fits all' approach is sometimes taken to the provision of information, which was not conducive to enabling them play an active role in their care.

For example, several patients told of how the information they were provided with at initial diagnosis was aimed at a much older cohort, and did not reflect the impact that the condition might have on younger people living with that condition. As such, they felt uninformed about the effect that their diagnosis may have on their lives.

> 'I was told I wasn't a typical case, which made giving me accurate information difficult, but what patient is a typical case? We each need our own information.'

This was a particular concern when individuals were being asked to participate in decision-making related to treatment decisions, given that they felt uninformed about potential side-effects of certain courses of treatment.

Other patients spoke of how the reality of their condition was not reflected in the information made available to them.

One said they felt like they had been 'banging my head off a brick wall' in making the case to nurses and their consultant that their condition did not affect everyone the same way, and that the information they were being given was consequently not relevant to them, particularly with regards to risks and benefits of possible treatment options.

Another said that: 'I'm always given information about dizziness. I don't experience dizziness. Just because lots of others with my condition do doesn't mean I do. I need it to be personalised.'

> 'I put on 6 stone because of the drugs I was taking and had to get a gastric band – I wasn't told that. I wasn't told how the drugs I was put on might affect my future.'

These perspectives back up the growing body of evidence which shows that one of the most important things that can be done to improve patient information and to increase its impact (e.g. greater patient activation[9] and greater shared decision-making[10]) is to provide individuals with specific, tailored information and education.[11] [12]

[9] Patient activation is a way of conceptualising and measuring the knowledge, skills and confidence an individual has in managing their own health and care. According to the King's Fund, 'Intervening to increase activation can improve a patient's engagement and health outcomes and is an important factor in helping patients to manage their health.' For more on patient activation see the King's Fund's 'Supporting people to manage their health: An introduction to patient activation' https://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/supporting-people-manage-health-patient-activation-may14.pdf.

[10] Shared decision-making can be defined as a process in which patients, when they are required to take a decision in relation to their health care, are offered the opportunity to review all treatment or care options available to them and actively participate with healthcare professionals in making that decision.

[11] National Voices (2014) 'Improving information and understanding'. Available at http://www.nationalvoices.org.uk/sites/default/files/public/publications/improving_information.pdf

[12] Patient Information Forum (2013) 'Making the case for information'. Available at http://www.pifonline.org.uk/wp-content/uploads/2013/05/PiF-full-report-FINAL-new.pdf

Finally, peer support groups were considered to be one highly useful way of ensuring that patients are able to access the kind of 'wrap-around' information that they need, for example the potential impact on employment, on their family, on their psychological wellbeing etc.

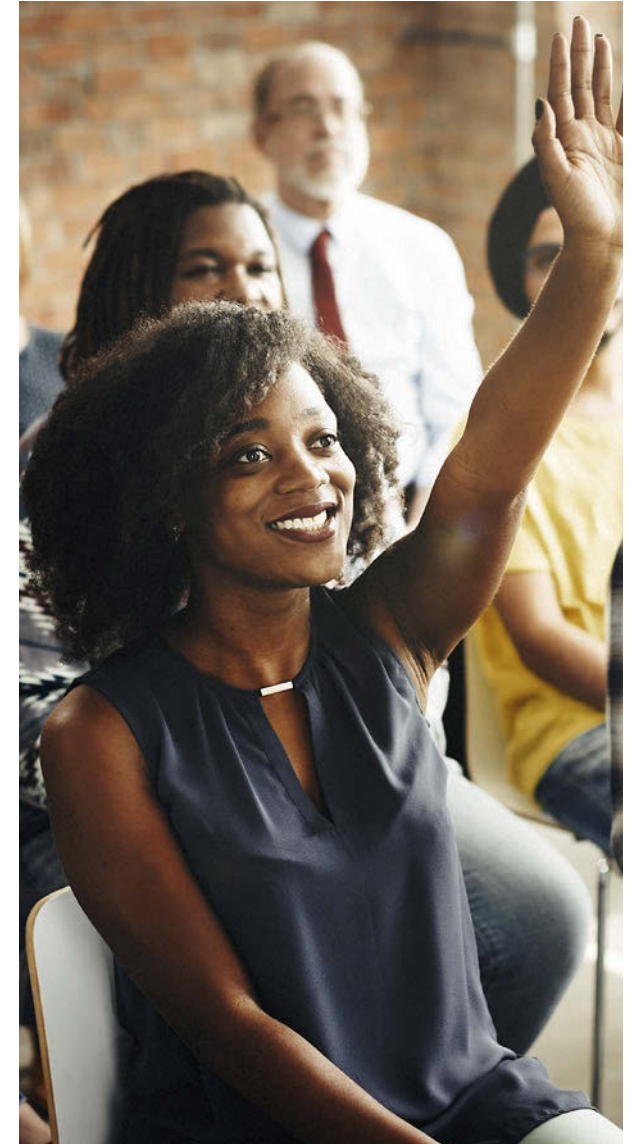### 6. Being supported to ask questions is vital

For many patients, being supported to ask questions was regarded as a vital component in ensuring access to the information they need.

'I ask a lot of questions anyway, it's just the kind of person I am. But I know that lots of people aren't like me, and they need to be helped to ask questions. I've been in so many consultations where I didn't really understand what was being said, and if I hadn't asked questions I'd have been left totally misinformed.'

Being prompted to formulate questions before a consultation (by, for example, being reminded to have three questions prepared prior to a consultation, or by being given test results in advance of consultations), and being encouraged to ask questions, was considered to be essential in fostering shared decision-making.

Many patients felt that they were not encouraged to ask questions, and it was clear that paternalistic approaches to care (which dissuade patients from sharing decision-making and prevent them from effectively self-managing) do persist in some areas of long-term condition management.

One patient, for example, spoke about a point in their patient journey at which their existing medication was no longer effective. Rather than being provided with information about alternative medication and being given the opportunity to ask questions, he reported being made to feel 'like I was taking up the consultant's time by asking questions, and so I just agreed with what he suggested, even though I didn't really know anything about the new treatment.'

A simplified model of the Case for Information:

'Infomediaries'
Health information specialists and health and care staff – providing information, signposting and navigation services

Quality consumer health information
Available in a variety of formats, throughout the health and wellbeing journey

Support resources
Decision aids; community-based self-management education; health coaching; telephone counselling etc

Good communications and support
To help people understand and make effective use of relevant health information; and to help inform choices

Increased satisfaction and reduced anxiety and stress

Education and support
To increase people's ability, confidence and motivation to change their behaviour, and to help inform choices

Greater patient engagement

More self-care of minor ailments

More shared decision-making

More self-management of long-term conditions

Better quality care

Greater clinical effectiveness

Enhanced patient experience

Improved patient safety

Lower costs
- ✓ Reduced demand for GP services and unplanned care
- ✓ More appropriate use of services, including screening rates
- ✓ Fewer hospital admissions and less time in hospital
- ✓ Less major surgery
- ✓ Reduced variation in procedures
- ✓ Safer, more efficient use of medicines
- ✓ Greater productivity, lower staff turnover, less absenteeism
- ✓ Reduced litigation and claims for compensation

Better outcomes
- ✓ Treatment in line with patient preferences
- ✓ Better adherence to treatment
- ✓ Safer, more effective use of medicines
- ✓ Healthier behaviours
- ✓ Improved health, quality of life and psychological wellbeing
- ✓ Increased self-monitoring
- ✓ Greater health literacy
- ✓ Reduced health inequalities
- ✓ Fewer complaints and medical errors

To see PIF's Case for Information report in full visit: https://www.pifonline.org.uk/wp-content/uploads/2014/11/PiF-Case-for-Information-Report-Final-Full-Report.pdf

It was felt that, often, patients are unable to fully comprehend issues discussed during consultations (primarily due to the anxiety of the consultation process), and so it is often the period after consultations that they most require clarification and information. One suggested solution, from our project participants, included the availability of a follow-up phone call or email with a clinician or nurse, which would offer the opportunity of asking questions that may have arisen following their consultation.

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

While health professionals expressed concern about patients accessing incorrect or inaccurate online information, patient participants were clear that they felt equipped to filter online information in order to ascertain quality and accuracy.

'I was given lots of information when I was first diagnosed but it just went over my head because I was in a bit of a mess psychologically. After the shock went I relied a lot on the internet for information. Everyone said 'don't just Google it' but I'm not stupid. I know which websites are reliable and which aren't. I know my nurses and consultant don't have that much time, so now I've got the websites that I trust I use them a lot.'

Several reported finding online information to be extremely useful in helping them to better understand the potential impact of living with their condition. Given that this information can be accessed whenever an individual wishes, it was felt to be of particular value when someone is first diagnosed, meaning that once the initial shock has subsided a patient is able to educate themselves about their condition and the options available to them.

Of particular usefulness, patient participants reported, was the peer support that is available online, with information from other patients being hugely valued for its relevance.

Also highlighted was the importance and reliability of online information provided by patient organisations; such information was felt to be of an extremely high standard and informed by others with lived experience of their long-term condition.

However, it was also highlighted that this reliable information can prove difficult to find unless signposted towards it (particularly for less 'activated' patients), with several patients speaking of how they 'don't know what they don't know' and of needing some level of support in identifying the information they need.

Healthcare professionals therefore have a vital role to play in being aware of, and signposting patients towards, patient organisation provided information.

8. Local leadership and information champions are needed

Despite being recognised as a positive intervention that results in clear and successful outcomes for patients, healthcare professional participants reflected that, often, the provision of high quality information for people with long-term conditions was not a priority due to a lack of intra-organisational leadership.

'We have a self-care lead within our CCG who is, I suppose, responsible for patient information. But they're funded for half a morning each week, so there's a real limit to what they can actually do.'

In the absence of a designated lead for patient information, it was felt that information-focused interventions are often not put in place because, as one participant reflected, 'it falls through the gaps between what we'd like to do and what is actually done.'

The concept of appointing designated Information Leads within CCGs and NHS trusts was supported, backing up the recommendation contained within PIF and MHP's 2015 'Is Knowledge Power?' report, which called for Information Leads to be appointed within CCGs and NHS trusts and armed with 'an appropriate mandate to ensure consistent and effective delivery and pursuit of commitments and aspirations for empowerment through information.'[13]

Also supported was the option of incorporating patient information responsibilities into existing roles within services.

[13] Patient Information Forum & MHP Health (2015), 'Is knowledge power?' Available at http://www.pifonline.org.uk/wp-content/uploads/2015/03/Is-knowledge-power.-Using-information-and-support-to-empower-patients..pdf

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

Despite unanimous support for the importance of information access as a way of improving outcomes for people with long-term conditions, healthcare professionals and commissioners were of the belief that they often simply do not have sufficient time to enable them to provide the kind of information access that they are aware would be desirable.

> 'I'm aware that we can't just go through a tick box exercise. It isn't just about giving information, we need to be able to explain it and individualise it. Do I always have time to do this though? No.'

For GPs, in particular, time was cited as the single biggest barrier preventing them from providing the level of information provision they would like. With short consultation times, the key role for GPs was considered to be signposting patients to the information they require.

An 'information directory' for GPs, which would allow GPs to refer patients on to reliable information sources, was thought to be essential in supporting this.

Some examples of good practice were cited, however. One healthcare professional told of how, in their service, all patients are offered a 1–2 hour session with a nurse upon first diagnosis. The discussion in this session is patient-led, and affords the patient the opportunity to ask any questions they may have, or discuss in depth the impact of their diagnosis and their possible treatment and care options.

While this may not be feasible in all services, it was clear that designated time in which patient-led conversations could take place between patient and health professional following a diagnosis would be welcome.

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

'Let's be honest, we are in a cost-focused environment and we need to be shown how improved patient information will save us money. That, sadly, is the over-riding thing.'

Given the barriers that were identified by healthcare professionals, it was deemed to be vital for commissioners to have a greater understanding of the importance of access to information for people with long-term conditions.

Commissioners, on their part, accepted that patient information was vital but also stated that they needed the evidence (which they felt they did not currently have) to show the cost-effective outcomes that can be achieved through further embedding access to information within the pathway for people with long-term conditions.

They were also keen, however, to point out that they do not just pay lip service to the importance of the patient experience, and that improving the patient experience was a key consideration for them when commissioning services.
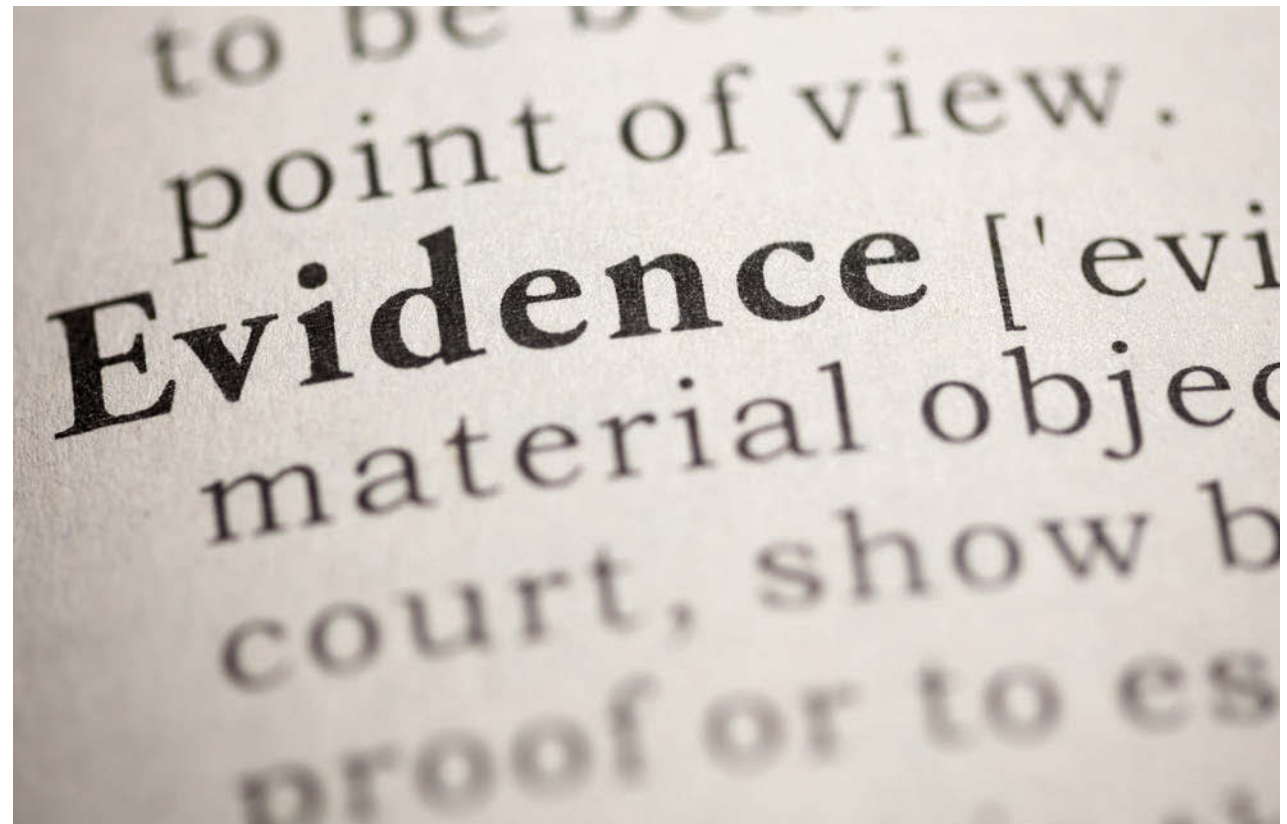
In the first phase of PIF's Perfect Patient Information Journey project, in addition to the staging of focus groups, workshops and interviews, research was undertaken into previous examples where information provision has been (or has attempted to be) embedded into the provision of healthcare across patient pathways.

During the course of this research, which looked at a number of case study examples, some key themes emerged. Below is a description of some of these key themes, along with short overview of three of the case studies identified:

Information champions within services are vital

Evident from the research was the need for designated Patient Information Leads within services, or at least a shared decision-making champion with responsibility for overseeing information access points.

These need not be clinical staff, and could be key workers or a member of the reception staff who is charged with overseeing aspects of care, e.g. sending feedback questions and health plans to patients, providing information prior to appointments, etc.

A key lesson from the Health Foundation's MAGIC (making good decisions in collaboration) programme (which sought to integrate shared decision-making into the practice of various healthcare services across Newcastle and Cardiff), for example, was that 'having a 'champion' at senior level (in the team and the wider organisation) can help prioritise shared decision-making.'[14]

Evaluation of the Year of Care programme (which was designed to embed personalised care and support in routine practice for people with long-term conditions, supporting their self-management and developing generic principles for the specific condition of diabetes) also highlighted the importance of clinical leadership, and of (in particular) primary care champions.

This evidence not only supports the perspectives of health professionals and commissioners who participated in PIF focus groups and interviews, but also supports the recommendation made in PIF's 'Making the Case for Information' report that healthcare providers 'should have a Board Director responsible for the provision and monitoring of information and support for people, with dedicated personnel and resources to deliver it.'[15]

[14] Health Foundation (April 2013) 'Implementing shared decision making: Clinical teams' experiences of implementing shared decision-making as part of the MAGIC programme'. Available at: http://www.health.org.uk/publication/implementing-shared-decision-making

[15] Patient Information Forum (2013) 'Making the case for information', p.5. Available at http://www.pifonline.org.uk/wp-content/uploads/2013/05/PiF-full-report-FINAL-new.pdf

Dedicated training time is essential for staff buy-in

Regardless of the quality of information on offer to patients, the research impresses the vital component of staff 'buy-in'. Very simply, without the requisite attitudinal changes or skill development, it can be considered extremely difficult to ensure the kinds of information integration required.

The research does, though, highlight several ways of ensuring that staff buy in to the programme, and provides key learning points for consideration. The Linda Jackson Macmillan Centre (LJMC), based within the Mount Vernon Cancer Centre in Middlesex, for example, introduced 'Patient Prescription Pads' and a satellite information point to their service as part of the National Cancer Information Prescriptions Implementation Programme (see case study).

While the intervention was judged to have been successful in increasing patient engagement and widening access to information, it was observed that additional dedicated training time for staff would have been helpful in ensuring understanding of the importance of information provision and further improving outcomes. For some older consultants, in particular, it was felt that additional training would be vital in ensuring the attitudinal changes required.

A further example of the importance of staff training comes from the NHS Tower Hamlets Year of Care pilot site, where a number of interventions were introduced to prepare patients for participation in care planning. In advance of their implementation, a half day of additional training was provided to healthcare assistants, managers, administrators and receptionists, in order to successfully encourage and secure cross-organisational engagement.[16]
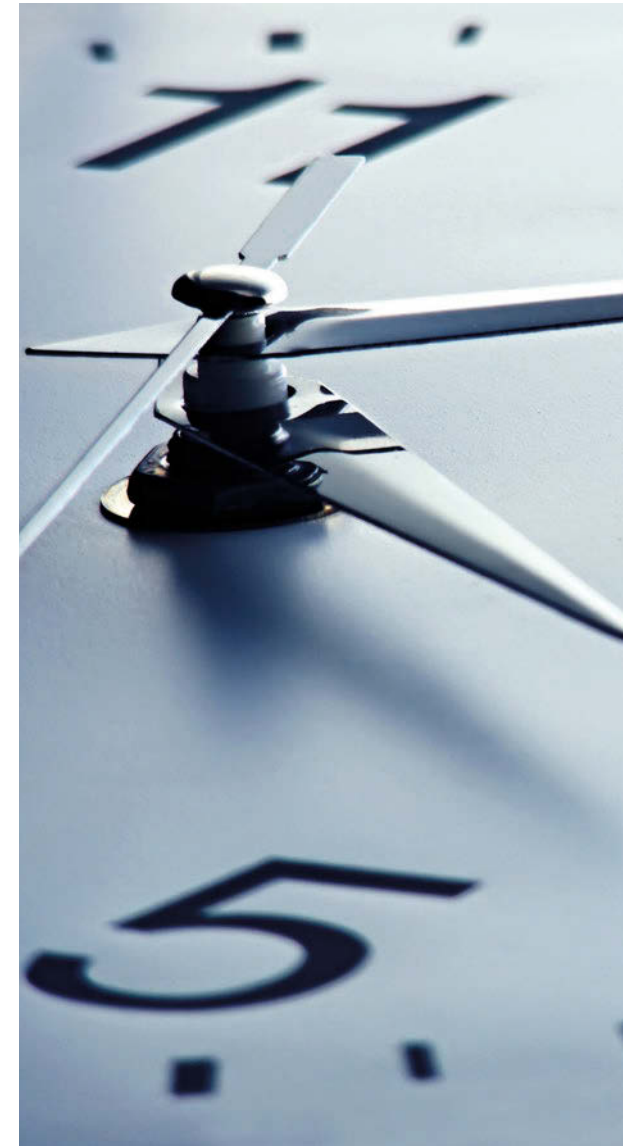
Case study: Patient prescription pads at the Lynda Jackson Macmillan Centre

At the Linda Jackson Macmillan Centre (LJMC), situated within the Mount Vernon Cancer Centre in Middlesex, 'Patient Prescription Pads' and a satellite information point (iPoint) have been introduced as part of the National Cancer Information Prescriptions Implementation Programme.

The aim of the pads, which were created with the clinical nurse specialists based within the Centre, was for them to be used by any professional providing patients with information (e.g. doctors, clinical nurse specialists, dieticians, radiographers, etc.).

For any information they wish the patient to have in relation to their treatment, e.g. side-effects, the relevant box is ticked on the prescription pad (including the correct format for that individual patient, something which enables tailoring to the individual needs of the patient depending on where they are at in their journey).

Patients then hand the pad to an information point manned by volunteers, who print all of the relevant information.

75% of patients surveyed after using the iPoint service, reported having all the information they needed as a result of the service, and patient engagement has increased since the introduction of the information point.

However, the project has experienced challenges which act as key learning points. A significant number of patients attending LJMC, for example, had not visited the iPoint, with some confusion on their part as to exactly what its purpose was.

Linked to this was a perception that, due to a lack of staff buy-in across the service, key messages regarding the pads and the iPoint had not been disseminated as extensively as expected.

Additional training time for staff was felt to be required in order to ensure the buy-in necessary to fully support patients in their usage of the pads and iPoint.

Staff involvement in the development of tools is crucial

As well as ensuring dedicated staff training time, the research also highlighted the importance of staff involvement in the development of tools as another way of ensuring their buy-in.

At the MAGIC programme's pilot at the Cardiff and Vale Breast Centre, University Hospital, for example, a crucial facet of the project was the development and implementation of a treatment option grid. The grid aimed to help patients to view and assess their treatment options (including the features, risks and benefits of each option) laid out clearly before them, along with answers to frequently asked questions.

However, while they were a success, it initially proved a challenge to ensure all clinicians used the option grid, as some were not involved in developing the tool and were not satisfied with its content. It was concluded that 'consultants might have used the grid more enthusiastically and systematically if they had been more closely involved in its development.'[17]

Case study: The Health Foundation's MAGIC programme

The MAGIC (making good decisions in collaboration) programme was focused on integrating shared decision-making into the practice of various healthcare services in sites across Newcastle and Cardiff, with phase 1 of the programme running from August 2010 until January 2012, and phase 2 running from May 2012 until October 2013.

The main features of the programme were:

▸ Use of shared decision-making tools, including brief decision aids

▸ 'Ask 3 Questions' campaign materials (which prompted patients to ask three simple questions at consultations to draw out information from the professionals involved in their care)

▸ The design and use of decision quality measures, to measure how effectively patients absorbed key information.

Key lessons from the programme were that:

▸ Brief decision aids were found, across all sites, to provide a 'more systematic and consistent approach' to conducting patient conversations, and of ensuring that patients had retained key information.

▸ Option grids were found to work extremely well as a way of embedding information and tracking its use, with clinical involvement in the development of the grid being a key determinant of its success.

▸ Decision quality measures were found to be useful for nurses in highlighting low levels of knowledge among patients, and helping to begin to change the way they communicated information to patients.

▸ The use of 'Ask 3 Questions' materials was evaluated to possess the potential to facilitate more collaborative and informed decision-making.

Health Foundation (April 2013) 'Implementing shared decision making: Clinical teams' experiences of implementing shared decision-making as part of the MAGIC programme'. Available at: http://www.health.org.uk/publication/implementing-shared-decision-making

Patient information is a job for everyone

All professionals across relevant services have a role to play[18]. From reception staff and volunteers to nurses and consultants, all are vital in enabling effective information access. At the Year of Care's Tower Hamlets' site, for example, they 'discovered the central importance of the receptionist and administrators in explaining, engaging and encouraging patients to be involved in this new way of working.'[19]

Non-clinical professionals played an important role in the MAGIC programme, too. At Newcastle Hospital's obstetrics service, for example, administrative staff were given the responsibility of identifying women who had undergone a previous caesarean section and sending a shared decision-making information pack to them.[20]

Such an approach not only reduced the burden on clinical staff, but also ensured wider organisational buy-in to the concepts that the project was seeking to embed within the service, once the obvious benefits were made apparent to the administrative staff.

There were challenges, however, with administrative staff being initially concerned about the additional workload. Such challenges were overcome through, firstly, ensuring staff were aware of the significant benefits of a shared decision-making approach and, secondly, initially trialling the approach with one receptionist, in order to allow the wider team to gauge the costs and benefits of their involvement.

[16] Year of Care (June 2011) 'Pilot case studies', p.34. Available at: http://www.health.org.uk/sites/health/files/YearOfCare_PilotCaseStudies_report.pdf

[17] Health Foundation (April 2013) 'Implementing shared decision making: Clinical teams' experiences of implementing shared decision-making as part of the MAGIC programme', p.37. Available at: http://www.health.org.uk/sites/health/files/ImplementingSharedDecisionMaking.pdf

[18] The production and provision of high quality health information is highly skilled. PIF champions and enhances the expertise of people working in the field of health information and support.

[19] Year of Care (June 2011) 'Report of findings from the pilot programme', p.46. Available at https://www.diabetes.org.uk/upload/Professionals/Year%20of%20Care/YOC_Report.pdf

[20] Health Foundation (April 2013) 'Implementing shared decision making: Clinical teams' experiences of implementing shared decision-making as part of the MAGIC programme', p.30. Available at: http://www.health.org.uk/publication/implementing-shared-decision-making

SPREAD YOUR MESSAGE

Case study: Year of Care programme for patient-centre care

The Year of Care partnership programme was designed to embed personalised care and support in routine practice for people with long-term conditions, supporting their self-management and developing generic principles for the specific condition of diabetes, which was employed as an exemplar case.

The main features of the programme were:

▸ The implementation of a collaborative care planning consultation between the individual and health professional on all of the individual's health issues, with shared decision-making and support for the individual to enable identification of patient goals, actions and needs for information. This replaced the annual surveillance review which had existed for diabetes, which has been described as a 'tick box activity'.[21]

▸ Agreeing and sharing a care plan.

▸ Sending test results prior to consultation, in order to inform the planning process.

▸ Use of a healthcare survey to assess whether patients are receiving the information they need from their local services.

▸ Use of a consultation quality index to explore the patient's personal experience of the consultation.

NHS Tower Hamlets acted as one of the programme's pilot sites. Here, structured education sessions were provided for diabetes service users, and a DVD and workbook were made available in three languages. Other resources made available included:

▸ Self-care directory

▸ Menu of services

▸ Care plan pack for patients

▸ Posters and leaflets

▸ Care planning template

▸ Information sheet for pilot practices

In Tower Hamlets, the pilot was found to have a 'definite and dramatic impact' on the lives of people with diabetes in the borough. In particular, patients reported feeling more in control both during the consultation and in their daily lives; positive changes that were recognised and felt by staff too. Positive behaviour change was also seen in greater attendance at clinics, with improved biomedical outcomes and an increase in staff productivity also being observed.

Year of Care (June 2011) 'Report of findings from the pilot programme'. Available at https://www.diabetes.org.uk/upload/Professionals/Year%20of%20Care/YOC_Report.pdf

[21] Diabetes UK, 'Year of Care'. Available at https://www.diabetes.org.uk/year-of-care

Supporting patients to ask questions is a proven way of increasing activation, collaboration and shared decision-making

Echoing the perspectives of focus group and interview participants, the case study research highlights the positive impact that supporting patients to ask questions of their healthcare professionals, in order to obtain the information they need, can have on increasing their levels of activation.

As part of the MAGIC programme, for example, patients were provided with 'Ask 3 Questions' campaign materials (such as flyers, handouts, pens, posters, etc.), which encouraged them to ask three questions at consultations with the aim of encouraging increased information access and shared decision-making.[22]

Three guide questions ('What are my options?'; 'What are the benefits and possible risks?'; 'How likely are these risks and benefits?') were provided, with local variation to these questions being encouraged.

While at the time of evaluation it was considered too early to assess the full effectiveness of the 'Ask 3 Questions' campaign, anecdotal evidence from the programme suggests that 'Ask 3 Questions' certainly has the potential to lead to more collaborative and informed decision making.

Further evidence for supporting effective question asking comes from a pilot study based in five community health centres in New York, where under-represented minority patients were observed to ask fewer questions in healthcare settings and subsequently experience greater difficulty in understanding the information provided to them.

The study centred around implementation of an intervention involving project staff speaking with patients ahead of current or upcoming consultations, and engaging them in a structured conversation around the decision-making process, with the aim of supporting the patient to formulate questions ahead of their engagement with healthcare professionals.

The intervention was found to have had a hugely positive impact on the cohort of patients targeted, with a significant increase in patient activation levels being observed following its delivery.

The study did, though, differ from the MAGIC programme in cautioning against the prescription of questions and instead strongly favouring questions that arise purely from patient-generated concerns, so as to ensure the questioner is provided with the information of greatest import to them.[23]

[22] Health Foundation (April 2013) 'Implementing shared decision making: Clinical teams' experiences of implementing shared decision-making as part of the MAGIC programme', p.18. Available at: http://www.health.org.uk/publication/implementing-shared-decision-making

[23] Deen, D., Lu., W.H., Rothstein, D., Santana, L., Gold, M.R. (2011) 'Asking questions: the effect of a brief intervention in community health centers on patient activation'. Patient Education and Counseling, 84 (2), pp.257.

Case study: Brief patient activation intervention in New York community health centres

In 2009, five community health centres in New York adopted an intervention designed to combat low levels of activation among patients, particularly those from minority and low-income groups, who tend to ask fewer questions and with whom clinicians tend to communicate less collaboratively.

The intervention focused on encouraging effective question-asking, to ensure patients were better informed and more able to participate in collaborative decision-making. It followed a template structure:

1 Project staff approached patients waiting for appointments with their clinicians.

2 The patient was asked to describe a recent decision they had made, and to consider the questions they asked to help them make that decision.

Using these statements, the interviewer clarified the definition of a question and ensured the patient shared their understanding of a decision, as well as the role of questions in making decisions.

3 The conversation would move on to the reasons for the patient's current visit to the centre (e.g. a new complaint, a follow-up, medication change).

4 Together, the interviewer and patient would brainstorm questions that may inform decisions made by the patient during their current or upcoming consultation.

5 These questions would then be jointly prioritised by the interviewer and patient, with the patient being given their prioritised list to refer to during their consultation, to assist them in the question-asking process.

The intervention achieved highly positive outcomes. Prior to the intervention, more of the 252 patients interviewed were assessed (using a Patient Activation Measure[24]) as being at lower levels of activation, than the national norm. However, one-third of participants moved from lower levels of activation to higher levels following the intervention, with the intervention being found to result in patients asking more and better questions of their doctors and to recognise the importance of asking questions in the decision-making process.

Deen, D., Lu., W.H., Rothstein, D., Santana, L., Gold, M.R. (2011) 'Asking questions: the effect of a brief intervention in community health centers on patient activation'. Patient Education and Counseling, 84 (2), pp.257 – 60.

[24] A Patient Activation Measure (PAM) is a validated, commercially-licensed tool that enables healthcare professionals to understand a patient's 'activation level', i.e. the knowledge, skills and confidence they have to manage their long-term condition. The tool involves individuals undertaking a survey, after which they receive a PAM 'score' of between 0 and 100. The score places the individual at one of four levels of activation, each of which provides insight into a range of health-related characteristics, including behaviours and outcomes.

Pathways must be flexible, integrated and responsive

Across several case studies, it was clear that increasing the flexibility, responsiveness and integration of pathways to ensure information access points are embedded was vital.

At the MAGIC programme's pilot sites at Freeman, Wansbeck and North Tyneside Hospital urology clinics, for example, the pathway was initially a 'one stop shop' model whereby patients received a diagnosis, processed it briefly, and then decided what to do in terms of their treatment and care all in one appointment.

However, it was felt that patients were being rushed into a decision and therefore were not always making informed choices. In response, the pathway was changed so that patients received their diagnosis, and were then given an information booklet to take home and read in order to formulate questions to ask before making a decision.

The project report from the pilot concluded that 'flexible patient pathways are needed to support the implementation of shared decision-making, in order to be responsive to the needs and preferences of individual patients'[25]; a key lesson when seeking to develop a perfect patient information pathway.

Such an example of a flexible, integrated patient pathway comes from the Somerset community-based self-care support service for adults with persistent pain. The service, which seeks to support health literacy and promote self-management, offers a range of services and support for patients at different stages of their patient journey.

Central to its success has been that the clinical leader of the service has been allowed to work with commissioners and service users to construct the entire service according to a core set of agreed principles, in order to make it as flexible, responsive and integrated as possible.

By taking charge of the pathway integration rather than leaving it for the patient to do, it has 'developed a new organisational form that is itself a challenge to the traditional silos of different forms of care.'[26]

In embedding key information access points within the pathway, the service reflects both the perspective of focus groups and interview participants and PIF's recommendation (made in its 'Is Knowledge Power?' report [27]), that information has to be seen as a core part of any patient pathway care and that it must be delivered as a standard part of engagement.

[25] Health Foundation (April 2013) 'Implementing shared decision making: Clinical teams' experiences of implementing shared decision-making as part of the MAGIC programme', p.24. Available at: http://www.health.org.uk/publication/implementing-shared-decision-making

[26] Collins, A., and Corrigan, P., (November 2012) 'Somerset Community-Based Self-Care Support Service for Adults with Persistent Pain'. Right Care Casebook Series, p.10. Available at: https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2016/09/Casebook_Somerset-CCG_-Pain-Service.pdf

[27] Patient Information Forum & MHP Health (2015), 'Is knowledge power?' Available at http://www.pifonline.org.uk/wp-content/uploads/2015/03/Is-knowledge-power.-Using-information-and-support-to-empower-patients..pdf

Case study: Somerset community-based self-care support service for adults with persistent pain

The Somerset Pain Management Service is a single entity that incorporates a wide variety of different services into one integrated, community-based pathway. It is primarily aimed at enabling adults living with persistent pain to achieve high-levels of health literacy, increase their levels of activation, and improve their ability to self-manage, and stands as an example of how an integrated pathway can be developed, which embeds within it the provision of information to service users.

There are four main components of the service, each of which has facets, outlined below, that facilitate and support improved access to information for patients:

The clinical service

▶ Provides a full assessment of the patient's pain.

▶ Provides up-to-date, relevant information about the patient's pain and treatment, as well as support and self-management options available to them.

▶ Supports collaborative personalised care planning (adhering to Department of Health best practice guidance), which involves discussions around options, including self-management programmes and telephone coaching support.

Training and support for staff

▶ An on-going training programme for GPs and other healthcare professionals is provided, which aims to increase their knowledge and skills in relation to supporting patients to self-manage, and increasing patient activation.

Access to peer group support

▶ An expert patient programme, delivered by trained and accredited peers, is made available to patients. The course includes discussion, peer support, supported goal-setting and action planning.

▶ Patient activation is a primary outcome measure that is assessed before and after the programme.

Online support and signposting

▶ For those unable or unwilling to attend the programme, an online self-management programme is available.

▶ An online personal organiser is also available to all patients during and after their engagement with the service. It includes a web browser that helps people find personalised information about managing pain; a local user-updated service directory; personal trackers to support people in tracking and maintaining progress towards goals, and a social networking site for people living with persistent pain.

Collins, A., and Corrigan, P., (November 2012) 'Somerset Community-Based Self-Care Support Service for Adults with Persistent Pain'. Right Care Casebook Series. Available https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2016/09/Casebook_Somerset-CCG_-Pain-Service.pdf.

Key Recommendations

Commissioners

► Commission high quality information resources and services for people living with long-term conditions, which: are responsive to the changing needs of patients and developed with service users; provide relevant and appropriate information throughout the patient journey; are supported by staff.

► Ensure services and staff are aware of their obligations to provide high quality health information to people living with long-term conditions, including by commissioning training on the importance of information provision and delivery.

► CCGs to appoint one member of their governing body to lead on the provision of high quality information within commissioned services.

Health services

► Ensure provision of high quality information is a key objective of all multi-disciplinary teams with responsibility for overseeing long-term conditions services.

► Appoint 'information champions' within services to oversee the provision of information to people living with long-term conditions.

► Map the pathway contact points where information either is or could be provided, and ensure that responsibilities for providing information at these contact points are confirmed.

► Ensure provision of high quality information is a key development objective contained within personal development plans for all relevant staff, and that the importance of health information (and shared-decision making more broadly) is incorporated into existing training and education sessions.

Healthcare professionals

► Ensure awareness of the key responsibilities and contact points in your service pathway related to the provision of information.

► Ensure awareness of high quality sources of information, and utilise these sources when signposting patients, including within consultations and care plans.

► Ensure that access to information is a key objective contained within all personal development plans.

► Co-design and co-produce, alongside patients, information packs and other resources to provide to newly-diagnosed patients.

► Participate in the development of shared decision-making tools, such as option grids.

► Ensure patients' information needs and requirements are monitored through the patient pathway, using tools such as decision quality measures.[28]

[28] Decision quality measures are tools that utilise series of questionnaire measures to identify an individual's understanding of their treatment and care options, their preferences, their ability to decide, and their choice of treatment or care.

Next steps for PIF

▶ Develop a Patient Information Commissioning Toolkit to raise awareness of the evidence and policy drivers that support the commissioning of high quality information.

▶ Develop a series of resources to support health services to measure and improve how they provide information to service users, informed by the principles outlined in this report.

▶ Deliver a pilot of the resources and evaluate the impact to service users and the service in improving the provision of health information.

If you would like to keep in touch with PIF's ongoing work in this area, and find out more about the tools we develop and our project evaluation, you can join our mailing list by emailing neil.cowan@pifonline.org.uk

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

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