Making the case: evidence based patient information

How can
evidence based
patient information
improve services?

Contents

Making the Case for Evidence Based Patient Information: Final Report

January 2019

Background

On behalf of Health Education England, a group of library and knowledge specialists across the NHS in England worked together on a shared project to explore how evidence is used in the creation of information for patients.

Project group

The project group consists of:

- Emily Hopkins, Health Education England
- Deena Maggs, The King's Fund
- Victoria Treadway, NHS RightCare
- Vicki Veness, Royal Surrey County Hospital NHS Foundation Trust
- Jacqui Watkeys, Walsall Healthcare NHS Trust
- Suzanne Wilson, Northumberland, Tyne and Wear NHS Foundation Trust

The project sponsor is Ruth Carlyle, Head of Library & Knowledge Services and Technology Enhanced Learning, HEE Midlands and East.

Contributions were also received from Liz Askew, Walsall Healthcare NHS Trust (Literature searching) and Nicholas Willsher, The King's Fund (animation).

The project ran from April 2018-January 2019.

Why does patient information need to be evidence based?

The need for patient information to be evidence based is driven by a number of strategic priorities including patient experience, self-management, shared decision-making and health system sustainability. Engaging patients and the public is a key priority at both national and local level throughout the NHS. Outlined in the Five Year Forward View, 2014 "we will do more to support people to manage their own health - staying healthy and making informed choice of treatment" and in recent guidance from NHS England (Involving people in their own health and care: statutory guidance for clinical commissioning groups and NHS England, 2017) it states that by involving "people in their health and care, [they] experience better quality care and improved health and wellbeing, and the system makes more efficient use of resources."

The Power of Information, the ten-year information strategy from the Department of Health (published in May 2012), outlines a framework for transforming information within the NHS.

In the context of libraries, the 'Knowledge for healthcare framework for NHS library and knowledge services in England 2015-2020', sets out the role of NHS libraries, it highlights using "the expertise of

their staff to ensure that NHS bodies, staff, learners, patients and the public have the right knowledge and evidence, when and where they need it."

Aims

1. To influence and advocate the importance of evidence for health information for patients, carers and the public in healthcare settings.
2. To reflect on how to influence key stakeholders and develop a set of case studies and notes which will support others to achieve this within their local NHS settings.

Objectives

1. To undertake a review of the evidence on evidence for health information (literature and learning from networks).
2. To undertake a mapping exercise to produce a snapshot of existing processes and policies around the production of health information in three local NHS Trusts.
3. To conduct an "influencing exercise" within local NHS Trusts to explore the feasibility of librarians and knowledge specialists becoming embedded in the production of health information.
4. To produce outputs that "make the case" for evidence based health information that will be used by local library and knowledge services to advocate for the use of evidence in health information for patients, carers and the public, as a core strand in delivering Knowledge for Healthcare.
5. To produce a final report on the learning and successes achieved during the project.

Expected benefits

The expected benefits of the project are that:

- Evidence based health information will result in well-informed and empowered patients, carers and members of the public.
- Increased awareness amongst stakeholders regarding the expertise and role of librarians and knowledge specialists in the production of health information.

1: The evidence base – what is known?

An evidence review was undertaken to understand what is already known about evidence based health information. In addition, areas of good practice and experiential learning were captured via professional contacts in library networks from across the UK.

The literature

A review of the literature highlighted that while the need for patient information is acknowledged, the quality of patient information across NHS organisations is variable.

Organisations working to influence high quality patient information, such as the Patient Information Forum (PiF) have published a number of resources to support health care professionals and organisations to produce evidence based health information. A 2014 PiF report summarises the literature and makes a compelling case for high quality, evidence based patient information and its contribution to a wide range of healthcare priorities:

- It has a positive impact on service utilisation and health costs, patients' experience of healthcare and patients' health behaviour and status.
- It "unlocks" patient engagement, which is vital to help people manage their health, make informed decisions about their healthcare, and mitigate financial pressure on the health service.
- It makes good business sense: There are positive impacts on service use and costs, substantial capacity savings, significant returns on investment by increasing the self-management of long-term conditions and attracting customers.
- High quality patient information is necessary to enhance the patient experience; a key driver for NHS Trust boards and senior leaders.
- Actively involving people in decisions about their healthcare helps to reduce unwarranted variations in treatment.

A 2017 review article (Sustersic, 2017) highlights the role of well written and timely patient information leaflets in improving patient knowledge and satisfaction and inducing better adherence to treatment. However, it also acknowledges huge variation in the quality, appropriate use and effective evaluation of patient information.

Primary studies highlight additional benefits to the production of high quality patient information:

- It empowers patients and families and supports them to make evidence based decisions about their care (Wegwarth).
- It reduces unnecessary interventions including antibiotic prescribing and repeat GP consultations (de Bont, 2015).

It is also important to note that "high quality" information does not always specifically and explicitly mention the evidence base. Although this is implied, the link between quoting clinical evidence and making a leaflet understandable is sometimes not made in patient information policies.

Learning and reflections from library networks

Contact was made with library and knowledge service colleagues in England involved in patient information projects / roles. The aim was to capture learning and know-how around the issues and challenges facing library professionals trying to influence evidence based patient information. The project group sought to understand:

- What were the challenges of working locally with NHS Trusts?
- What helps to make the case locally and get involved in patient information?
- What advice or tips might be helpful for colleagues working on similar projects?

The key learning points from these conversations were as follows:

- LKS have a role to play in providing accurate evidence based patient information leaflets (PILs).
- Changes to the process or suggesting changes to the language used in leaflets can be challenging when influencing authors who were generally from clinical teams.
- Access to leaflets can vary from written form only, availability in local clinical teams or accessible online via the trust web site or portal.
- It is not always clear when leaflets were last updated or who was the original author. LKS involvement often led to the development of a systematic approach to routinely reviewing leaflets.
- LKS use of searching the evidence base to update leaflets can be patchy. However, it was acknowledged LKS have the appropriate skills and are best placed to undertake this work although capacity and resource of their service needed to be considered.
- LKS have a role in advocating the use of plain language.
- Using nationally produced leaflets had its place but there was merit in maintaining leaflets that outlined local procedures.
- Finding stakeholders to champions LKS involvement, especially at board level was essential. Some trusts found they had greater engagement with board members from their involvement in PILs.
- Building on existing relationships was important; where an LKS had good links and was already seen as the "go-to" place for evidence generally (for example, for clinicians' own use) this was often a stepping stone to having the opportunity to provide the evidence for patient information leaflets.
- It is important to think about how to demonstrate impact and cost/benefit of LKS providing this support

A full account of the conversations held is in Appendix 2.

2: Influencing evidence based patient information

An influencing exercise was undertaken in three NHS Trusts. This involved three members of the project group who currently work in NHS Trusts undertaking the following steps:

- Establishing an understanding of existing processes and systems in place locally for the production of patient information.
- Making contact with key individuals involved in these processes to gain an understanding of the opportunities and challenges.

Individual reflective case studies have been captured by the library professional working in each NHS Trust. Many reflections were specific to local organisational culture and processes; however, some common themes emerged:

- **The importance of timing**: The success of influencing a Trust to adopt an organisation-wide approach to evidence based patient information depends on organisational readiness.
- **Prioritisation**: One success factor is the degree to which evidence based patient information is prioritised and whether there is a responsible individual / group / team in place.
- **Understanding local processes:** Understanding what processes are in place already can assist LKS staff when making the case for using evidence.
- **Health literacy** is also a key component, and the link must be made between high quality information but also presenting it in a meaningful way and not assuming overly high levels of health literacy.
- **Importance of building relationships:** Building productive working relationships can take time but ultimately is key to the success of any influencing exercise.
- **High quality** patient information is acknowledged as important, however this can sometimes only focus on language and making the leaflets understandable and factually correct, rather than on actively using the evidence base. The link here may need to be made more explicit.
- **Service user engagement:** as with any service development involving patients and carers can help to enhance patient information by ensuring it is written in plain language and understandable.
- **Demonstrate how libraries can save time:** by highlighting the time saving element of using the library service to identify evidence for patient information, will encourage staff to utilise our skills and make the process more efficient for others.

3: Project outputs

The project group produced the following outputs to support other library and knowledge professionals in influencing evidence based health information in their own settings.

- Slidedeck - for LKS colleagues, for LKS leads
- Animation
- Stakeholder map
- Further information resources

4: Conclusions, recommendations, next steps

Conclusions

The final conclusions from the project as a whole are as follows:

- Evidence based health information makes a positive contribution to health care systems, including empowering patients and families, supporting evidence based decision-making and mitigating financial pressures.
- The need for evidence based health information is aligned with a number of high-level strategic priorities and drivers, including patient engagement, patient experience and shared decision-making.
- Influencing evidence based health information is not straightforward for library and knowledge professionals; our ability to influence is dependent on a range of factors including local organisational culture and priorities.
- Sharing learning and experiences between library and knowledge professionals is a valuable and worthwhile approach to expanding our capabilities around influencing evidence based health information.

Next steps

- A blog post will be published on the Knowledge for Healthcare site in 2019 to promote the findings of the final report which will be added to the PPI project pages.
- A blog post will be published on the King's Fund web site to promote the work library and information professionals play in providing evidence based information.
- Project findings and outputs will be cascaded to online networks (e.g. #ukmedlibs and #uklibchat) and LKS leads, including the Quality Improvement Outcomes group
- Project findings and outputs will be presented at regional LKS/ network events – Midlands & East (Dec 2018), North (March 2019), London & KSS (Date TBC), South (subject to availability and date TBC)

Recommendations

- Patient information is a key part of our "offer" – whether a service has a dedicated role or not. If the LKS is championing evidence based practice in the organisation, patient information is part of that.
- Supporting evidence based patient information may require specific attention and a slightly novel approach; building on existing influencing skills and relationships with clinicians, as

well as having some good examples and reasons to hand during these conversations may help.

- It may help to make the link between patient information and providing tailored support to colleagues. Library and knowledge services should be encouraged to do this in the new national Quality Impact Outcomes. In the pilot QIO - standard 3 is about LKS facilitating access to, and driving the use of, evidence and knowledge across the organisation; standard 4 – responsive to user needs; standard 6 – effective and efficient; and obviously demonstrating impact is also key.

References

De Bont, G et al (2015) 'Patient information leaflets to reduce antibiotic use and reconsultation rates in general practice: a systematic review', BMJ Open; vol. 5 (no. 6)

Department of Health Power of Information (2012)

Health Expectations Sustersic M, Gauchet A, Foote A, How best to use and evaluate Patient Information Leaflets given during a consultation: a systematic review of literature reviews (2017)

NHS England Five Year Forward View (2014)

NHS England Involving people in their own health and care: statutory guidance for clinical commissioning groups and NHS England (2017)

Patient Information Forum Is knowledge power? (2015)

Patient Information Forum Making the case for information: the evidence for investing in high quality health information for patients and the public (2014)

Picker Institute Europe Coulter A, Ellins J, Swain D et al., Assessing the quality of information to support people in making decisions about their health and healthcare (2006)

Wegwarth, O; Wagner, G; Gigerenzer, G (2017) 'Can facts trump unconditional trust? evidence-based information halves the influence of physicians & non-evidence-based cancer screening recommendations', PLOS One; vol. 12 (no. 8)

Appendix 1: Reflective case studies

Case Study 1 : Overview of Evidence Based Patient Information

Aim

To scope current processes in place at an acute hospital around the inclusion of evidence in the creation of patient information and library and knowledge services support.

Who was contacted?

- Head of Clinical Governance
- Patient Information and Advisory Lead (PALS)
- Patient Experience Manager
- Equality and Diversity Lead
- Hospital Business Manager

Background and Current position

The EIDO Healthcare resource was procured 8 years ago by the hospital Business Manager and is available via the hospital intranet. The EIDO resource is an evidence-based patient information online library of over 320 leaflets relating to procedures and treatments available nationally. Healthcare staff at the hospital can use EIDO to support patients around informed consent about their treatment. A survey conducted in October 2018 with 67 respondents, highlighted a disparity of the in-house patient information produced across the organisation, what is produced and evidently if evidence-based. These findings were presented by the hospital Business Manager to Directors and resulted in an action plan involving Library and Knowledge Services. An audit of all patient information across the hospital was conducted in spring 2019, with a review of findings in summer 2019. As part of the action plan a conference on patient information and consent was held at the hospital in March 2019 attended by 110 staff.

**Patient Information and Consent Group**

Members: Communications IT Lead, Trust Business Manager and Library and Knowledge Services Manager

Aim: To produce an action plan for Directors on:

- The position on what information is provided to patients
- Processes involved in the management and tracking of patient information across the organisation
- If the information provided is evidence-based

Key Survey Findings and Action Plan

Who in your service produces the information for patients?

Answered 55%
Skipped 45%
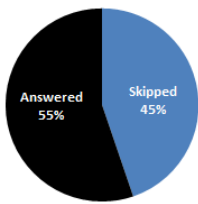
The number of responses, 45% who skipped this question indicated uncertainty around responsibility for who produced information for patients within services. This demonstrated a need for clear processes and communication at all levels within the organisation.

Group aim:

An audit was conducted for staff to submit information provided to patients. At a glance it presented an insight into what is produced across the organisation, the quality and if evidence-based.

What processes are involved in the production of information for patients?
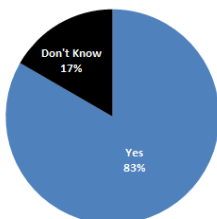
Skipped 51%
Answered 49%
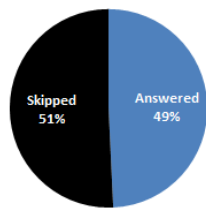
Just over half of those who responded were not aware of what processes were involved in the production of information for patients. Similarly this question correlates to another whereby 45% were not aware if there was a tracking system for the notification for expired patient information. This highlighted the need for better systems to be established across services to remove errors and risks to patients.

Group aim:

To scope how better process systems could be implemented to enable effective management of patient information and identify good practice to help patients make informed decisions about their care.
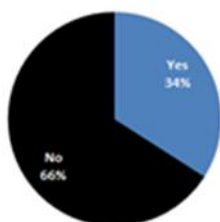
The creation of evidence-based patient information is critical for patients to ensure accuracy and reliability. 17% who responded were uncertain if this procedure was undertaken.

Is the information given to patients evidence-based?

Don't Know 17%
Yes 83%

Group aim:

As champions in the provision of evidence-based information, the role of library and knowledge services professionals was central in re-enforcing the importance of the production of good quality information. In the absence of the hospital Business Manager, the Library and Knowledge Services Manager co-ordinated a successful conference on patient information and consent attended by a range of hospital staff. The event was opened by a Trust Director and with presentations from consent and EIDO representatives. Library services provided a stall where attendees could find out more about evidence-based support in producing information for patients. The event also provided a great opportunity to showcase a HEE project by a group of library and knowledge specialists on how evidence can be used in the creation and review of information for patients.

Despite the EIDO system being available, 66% of staff were not aware of the resource. Whist other results showed that 69% knew how to access the system with a further 47 % requesting training.

Awareness of the EIDO system?

Yes 34%
No 66%

Group aim:

Library and Knowledge Services staff was trained as EIDO champions to raise awareness of the resource through promotion. Working with the communications team, a screen saver promoting EIDO was showcased on hospital PC's and a poster created was made available on all wards. In the 30 days prior to the patient information and consent conference, there were 90 individual downloads on EIDO by hospital staff. In the 30 days immediately following the conference there were 143 downloads. The average monthly downloads are 127, so the increase was probably attributable to the conference.

Case study 2: Mental Health, Learning Disabilities and Neurorehabilitation Trust

Background

This Trust provides mental health, learning disabilities and neuro-rehabilitation services in the north of England. The Patient Information Centre Manager co-ordinates and maintains patient information on behalf of the Trust.

The trust has a policy on *The Production of Accessible Information for Patients, Carers and the Public* which has been in place for several years. The policy highlights the importance of patient information to patient experience, "*ensuring that patients have greater power, protection and choice in key aspects of their healthcare*." It states that patient leaflets should meet the criterion in the NHS England Information Standard, which includes being evidence based.

Process

Library services are included as part of the process either in delivering literature searches or by facilitating access to online evidence. All patient information leaflets are reviewed and updated on a three yearly cycle and follow the following steps:

- Justification and support for developing new information, without duplicating national or local work.
- It reflects existing patient information and links to other service priorities
- Content is checked and updates by clinicians responsible for the procedure or patient care in conjunction with the Patient Information centre.
- Information is evidence based and referenced appropriately, with support from library services.
- Resources will not endorse or promote products or third party services
- Patient information resources should be written in a concise and unambiguous style using plain English. Consider producing in other languages and making available in other accessible formats on request.
- Content – the information must reflect the procedure and must contain facts about risks, possible side effects, benefits or alternatives to the treatment, procedure or investigation. The evidence should be references.
- Authors should ensure appropriate review and consultation with service users, carers and stakeholders takes place.
- Staff in the Patient Information Centre will ensure corporate identity guidelines and accessible information guidance is followed.
- Draft information is checked for accuracy before being sent for approval to the appropriate director(s).
- Once formatted, completed resources are added to the Patient Information Centre website and database

Reflections

Having a documented process with an allocated patient information manager helps to give some visibility and governance to the production of good quality information.

Sourcing evidence for patient information is a core part of our literature search service. It can save clinical staff time and effort in identifying recent evidence.

Case Study 3: Overview of the provision of Evidence Based Patient Information

Aim

To investigate and understand the existing processes and procedures in place around the creation, provision and review of patient information leaflets in an acute hospital, and how library services might influence and support the process to ensure that all information made available is evidence based.

Background

Trust documentation states that 'Patient information is a key component of the patient journey and central to the overall quality of each patient's experience of the NHS'.

A number of documents are available via the Trust intranet to guide staff when they are creating or updating patient information leaflets.

- **Patient Information Policy**

  'Leaflet to contain other sources of information and key reference source(s) used in the leaflet's production.'

  'Training, the Patient Information Facilitator will provide workshops on producing quality, authenticated PILs.'

  'Patient Information Steering Group meets at regular intervals.'

- **How to produce quality, authenticated patient information leaflets (PILS)**

  'Provide key reference sources used in the compiling of the leaflet. These should be specific and evidence based

- **Patient Information Leaflet Self-Assessment Form.**

  '…information contains specific references of literature…provides assurance to the reader that the information is from a credible and evidence based source that is current and relevant.'

A comprehensive checklist must be completed when a patient information leaflet undergoes any change or a new leaflet is to be created, this must be counter signed by a senior clinician/manager.

Current Position

Further investigation identified that at present a Patient Information Facilitator is not in post and that the Trust's Patient Information Lead is responsible for overseeing the creation and review of Patient Information Leaflets, all leaflets are created in a house style and meet the Information Standard.

The importance of ensuring leaflets are understandable and well written is recognised and given perhaps greater emphasis than the source of any supporting evidence. All leaflets are available on the Trust website. It is the responsibility of the leaflet author to ensure and confirm that information sources used and referred to are evidence based.

In reality, there is little practical support in place to assist leaflet authors to ensure that the sources they refer to are evidence based. To date the Library Service has not been involved with the process.

Conversations

Having identified those in key roles, contact was made by phone and email and a meeting arranged with the Patient Information Lead, who was able to confirm that; the Patient

Information Policy is due for review, that a Patient Information Steering Group no longer meets and that there are no plans to reinstate the group. Quarterly training on leaflet creation referred to in the Patient Information policy is not currently taking place.

Following the initial meeting, leaflet authors will now be directed to the Library Service for help/training in accessing evidence based information. The Patient Information Policy is currently being updated and will include signposting to the Library Service.

Reflections

- **Time and Timing**

It takes time to identify key individuals and build relationships. This is an ongoing process.

Lack of time impacts on the ability of staff to update and create new patient information leaflets, this creates an opportunity for the Library Service to highlight the comprehensive and professional evidence searching services that can be provided and which can save Trust staff valuable time.

Timing is important, the point at which a policy or process is due for review can be an opportune time for the Library Service to become involved.

- **Understanding local processes**

Understanding what processes and procedures are already in place can assist Library professionals when making the case for using evidence. This requires a degree of persistence and making the most of existing contacts and building new relationships with other key individuals.

- **Prioritisation**

In this situation, although the process is well managed and the importance of well written, authoritative patient information is clearly recognised, there is a single part time member of staff responsible for overseeing the provision of patient information across the Trust.

Next Steps

- **Building Relationships**

Follow up with the Patient Information Lead to continue building a productive working relationship.

- **A Core Service**

Providing evidence searches and training are a core part of the Library Service. Providing assistance to Trust staff with the provision of patient information should be viewed in the same way and advertised and promoted along with other Library services and resources

Reflective record of conversations held during an influencing exercise within an acute Hospital.

Reflection 1

Details of conversation - who/when etc

Library Manager meeting with Patient Information Lead, October 2018.

What happened?

Unfortunately, the meeting was cancelled as the Patient Information Lead has been signed off on sick leave. At present there is no-one else within the team to cover the role in their absence.

So what?

Reinforces the difficulties of influencing and making contacts when key staff are unavailable. Also, it takes time take to build relationships and this is perhaps beyond the timings of this project.

Now what?

I will keep in contact to find out when the Patient Information Lead is back at work and then re-arrange to meet.

Reflection 2

Details of conversation - who/when etc

Library Manager meeting with Patient Information Lead, November 2018.

What happened?

I met with the Patient Information Lead to talk through the process of PIL creation, monitoring and review in the Trust and to try and gain a better understanding of how the actual process in place relates to that described in the Trust Patient Information Policy and other documentation on the intranet. A new post holder took over as Patient Information Lead after a staffing gap of approx 18 months, and works 2 days a week. Their main role is to maintain the spreadsheet of PILS which are available on the Trust website and check completed leaflets against the Information Standard. The Patient Information Lead's remit is much more concerned with the look and feel, font size, tone etc and if the leaflet meets the IS, than whether the information is evidence based. They are reliant on the author and the counter signatory (Senior Clinician, Consultant or Senior Manager) to confirm that they have consulted relevant evidence.

Staff updating or creating new PILS currently follow the Patient Information Leaflet Self-Assessment Form 2018, which was recently updated. This is a detailed checklist, leaflet authors must tick to confirm: 'The information contains specific references of literature that have assisted with its production. This provides assurance to the reader that the information is from a credible and evidence based source that is current and relevant.' The Patient Information Lead is currently updating the Patient Information Policy as this is now out of date and is looking to simplify the document. They confirmed that the Patient Information Group no longer meets and that there are

no plans to reinstate the group. The quarterly training on leaflet creation referred to in the current policy is not currently taking place.

So what?

 It was a useful meeting and I'm glad to have been able to talk to the key person involved. As the policy is currently being updating the Patient Information Lead agreed to include signposting to the Library in the new document and to amend the Self-Assessment form to direct staff to the Library team for help / training in accessing evidence based information. We also talked about mentioning the Library team as a source of help when the Patient Information Lead contacts staff by email to remind them to update leaflets.

Now what?

I'm not sure, although it was a useful meeting, I'm not sure quite how much of an impact I had. Going forward I think I'll speak to the Patient Information Lead again, perhaps by email, to suggest that as a library we promote to Trust staff that we are available to assist with providing the evidence and that, actually, this is just another of our core services.

Reflection 3

Details of conversation - who/when etc

Library Manager meeting with Patient Information Lead, November 2018.

What happened?

Following my meeting with the Patient Information Lead at the Trust, I sent a follow-up email thanking them for their time and providing the Library's contact details. This was so that the Patient Information Lead can sign-post staff to the Library team, for help conducting searches and/ or training in using healthcare databases, when they are updating or creating new leaflets.   During our meeting the Patient Information Lead had mentioned that staff often cite lack of time as a reason why they are unable to update leaflets so I also asked whether there would be any scope to add to the PIL assessment form next time it is updated. If it would be possible to include 'Have the Library Team (xxx@nhs.net) conducted an evidence search for you?'   This would help ensure that more leaflets are created using the most up to date evidence, and to assist and encourage those who aren't updating leaflets because of a lack of time.

So what?

 I hope to continue to build a productive working relationship, however this may take some time.

Now what?

 I've yet to receive a response to my email, and may have to wait until the revised policy document is available. As a Library Service we will proactively market our evidence searching service as a tool to assist with creating and updating PILs.

Appendix 2: Learning from local library networks

Patient Information Librarian

Patient information leaflets currently produced at the trust are accessible on the web site. However, an initial issue was understanding how many patient leaflets are being produced in-house within the trust and how often these were reviewed. Through their role, they were aware that 'health' is the second most searched topic on Google. A concern was patients searching for information about their health conditions find information but have no knowledge of how to interpret or appraise the quality and authority. They felt LKS have a role to play in providing accurate evidence based patient information and can assist in adapting text to make leaflets more understandable for patients. New leaflets are uploaded and stored on to the trust web site but evidence searches carried out by the LKS to inform the content are added to Knowledgeshare.

Currently the LKS is setting up an overarching committee where updated or new PILs would be reviewed and signed off at a senior level. This group will initially include staff representatives but longer term the committee would aim to include a patient representation.

Resources have also been developed by the LKS to demonstrate best practice and quality in producing PILs. These resources include NICE guidelines, information from health charities, and suggestions of ways simplify language and again are accessible for anyone on KnowledgeShare.

Library and Knowledge Services Manager, at a Large Hospital/ Foundation Trust

The LKS team at the Hospital are heavily involved in providing evidence in the production of patient information and it is provided for in the policy. The library has a literature search protocol for patient information, and an ordered list of evidence sources, to ensure this is done in a robust, consistent manner. Many of these documents were developed during the Library Manager's time as Clinical Librarian and further developed in the library service. Developing relationships with clinicians and within and across departments was naturally a key part of this role, and specifically targeting patient information, or doing anything differently here, wasn't seen as a separate priority at the time, rather it was one of the many types of information that the Clinical Librarian and LKS would provide – the need for good quality evidence and the role of the library in providing it was promoted and acknowledged for a variety of purposes, and patient information was a natural part of this.

Over time this has developed naturally and by word of mouth; and is now seen as a regular part of the library's offer – as one team uses the library to support their patient information, another team looking to do something similar would naturally follow the same process; essentially good practice has spread. It was due to these good relationships and custom and practice (and having robust processes such as the protocols) that when the Patient Information Policy was being developed, the Patient Information lead contacted the Library Manager to ask for their support and input. They also drew on examples from elsewhere – such as those on the Patient and Public Information Ideas Bank, particularly Blackpool Teaching Hospitals NHS Trust. The Cancer Manual was another natural next step for the service and again, looking at good practice elsewhere led to them looking at the NHS in Scotland, particularly NHS Lothian.

The Library Manager and the team are aware of challenges facing the production of patient information, such as whether the Information Standard will be kept – if this goes, they perceive it

may be one less driver to produce good quality patient information. This scenario is something they are aware of and thinking of. As with everything, the pressures of time and workload can mean sometimes it is difficult for clinicians to find the time to factor in contacting the LKS to request this support.

This example shows the effectiveness of building good relationships with colleagues across the trust and understanding their needs, as well as maintaining awareness of specific drivers (such as the Information Standard) and good practice elsewhere. By the Library Manager's own account, they didn't begin with a separate strategy around patient information, but it was something that developed out of positive relationships with their colleagues and became a natural step from their offer. Formalising it as part of the Policy built on prior work, rather than being the starting point for them. Essentially; good practice and a culture of evidence based practice were spread across the trust over time, and eventually formalised into the policy.

Patient Information Librarian

As a recently appointed Patient Information Librarian the reporting structure was to the Consent Committee within their trust as well as their line manager in the Library and Information Service. They initially carried out a patient leaflet audit which highlighted there were many leaflets created and maintained across different clinical medical team, and many were showing an expired 'review' date. The trust had not employed a central person to support patient information for 10 years. Reviewing PILs was not routinely carried out and finding authors willing to update content was difficult. The team were keen to demonstrate how their involvement would ensure evidence based information was available, easy to find and easy to understand.

Through the Patient Information role literature searches were offered to staff to support updating of PILs which took up a significant part of their role; updating content, checking sources and adapting the language to being clearer to patients. The patient information service can offer skills in organising information

They also recognised if PILs were not systematically updated this would be a risk for the organisation. The team found the Listening into Action" exercise helped in getting engagement from people at senior levels about the issue of risk Through this work LKS has experienced greater contact with the board and some of their biggest champions are non-exec directors.

 Ideally more resources to support this work would be welcome, especially for reviewing and updating the significant quantity of patient information leaflets.

Additional information

They see their role as:

- Facilitating the development of a single repository of information about healthcare at our hospitals. This has been launched but needs investment of time and admin support to become fully populated with the thousands of pieces of patient information we use; and to provide cataloguing, active management, version

- Developing Patient Information Leads across the Trust. Approximately 70 services that should each have a person responsible for tracking the leaflets they use, their review dates and identifying authors to update in a timely way. This is currently patchy at best.
- Setting up governance structures to quality assure the leaflets that are created and updated, particularly to try to mitigate risks to the Trust if the informed consent process isn't robust, but also to improve patient experience and shared-decision making
- Promoting health literacy principles, providing training for all staff and encouraging our organisation to be health literacy friendly.
- Act as a member of a working group aiming to achieve compliance with the Accessible Information Standard and have strong links with the equality team regarding translation of leaflets
- Working with the wider healthcare community to raise awareness of YourHealth as a tool to increase patient knowledge at the point of referral into the hospital; discharge or transition into other services.
- Assisting the Trust with their vision for eConsent and having high-quality, evidence-based patient information integrated into each eConsent record.

Outreach Librarian, at a Foundation Trust

The LKS role in supporting the production of patient information leaflets (PILs) is very established as a core service for about 10 years. It was developed from the outreach team after a decision was made to review leaflets aimed at 11 year olds. From there on, it has been expanded to all PILs across the trust. The outreach team have always worked in partnership with other teams across the trust on PILs.

The Outreach Librarian developed a patient information process to ensure all leaflets are up-to-date and meet the Information Standard. The workflow document outlines what level of amendments requires a review by the Outreach Librarian and what can be done by the author. LKS check high level reports and guidance but not primary evidence. The team also perform 30 annual audits for 30 randomly selected leaflets which check for version control, compliance, brand and grammar, relevant references and support groups inclusion. PILs are stored on a central resource accessible across the trust. This process and way of working was expanded across other LKS teams after a merger of two trusts to ensure consistency.

The Outreach Librarian felt this was an extremely valuable service where staff were generally compliant to the process. SWOT analysis of the service demonstrated positive compliance, it helps remove risk, it was cost-effective and most leaflets were regularly reviewed. However, it also highlighted some issues around a number of leaflets not going through the process and data stored locally on individuals' devices rather than centrally.

Appendix 3: Learning log

 Golden nuggets of learning

Learning log

No.	Golden nugget	Source
1	Health system considerations	
1.1	The need for patient information is acknowledged, but the quality of patient information across NHS organisations is variable.	Evidence search
1.2	In the literature, when patient information is described as "high quality", it doesn't necessarily mean "evidence based". Although this is implied, the link between quoting clinical evidence and making a leaflet understandable is sometimes not made in patient information policies.	Evidence search
1.3	High quality, evidence-based patient information has a positive impact on service utilisation and health costs, patients' experience of healthcare and patients' health behaviour and status.	Evidence search (PiF report)
1.4	High quality, evidence-based patient information "unlocks" patient engagement, which is vital to help people manage their health, make informed decisions about their healthcare, and mitigate financial pressure on the health service.	Evidence search (PiF report)
1.5	High quality, evidence-based patient information makes good business sense: There are positive impacts on service use and costs, substantial capacity savings, significant returns on investment by increasing the self-management of long-term conditions and attracting customers.	Evidence search (PiF report)
1.6	High quality patient information is necessary to enhance the patient experience; a key driver for NHS Trust boards and senior leaders.	Evidence search (PiF report)
1.7	Actively involving people in decisions about their healthcare helps to reduce unwarranted variations in treatment.	Evidence search (PiF report)
1.8	It empowers patients and families and supports them to make evidence based decisions about their care.	Evidence search (Wegwarth)
1.9	It reduces unnecessary interventions including antibiotic prescribing and repeat GP consultations.	Evidence search (de Bont, 2015)
2	LKS capacity	
2.1	There is a role for LKS in providing evidence support though capacity needs to be considered.	Interviews
2.2	Sourcing evidence for patient information is a core part of our literature search service. It can save clinical staff time and effort in identifying recent evidence.	Case studies (NTW)
2.3	Other health care roles, e.g. Apprentice or volunteer can help to audit patient information leaflets.	Case studies
3	Organisational culture	

3.1	The success of influencing a Trust to adopt an organisation-wide approach to evidence based patient information depends on organisational readiness.	Case studies
3.2	One success factor is the degree to which evidence based patient information is prioritised and whether there is a responsible individual / group / team in place.	Case studies
3.3	Trusts can focus on language and making the leaflets understandable and factually correct, rather than on actively using the evidence base.	Case studies
3.4	The quality of patient information produced in-house is variable. Case study survey: 91% of respondents (n=61) provide information to patients. When asked, "Is the information evidence based?", 17% (n=8) didn't know, and 19 skipped the question.	Case studies
3.5	Capacity of the person / team responsible for patient information may be limited.	Case studies
4	Organisational processes	
4.1	Access to leaflets can vary from written form only, availability in local clinical teams or accessible online via the trust web site or portal.	Interviews
4.2	It is not always clear when leaflets were last updated or who was the original author. LKS involvement often led to the development of a systematic approach to routinely reviewing leaflets.	Interviews
4.3	LKS use of searching the evidence base to update leaflets can be patchy. However, it was acknowledged LKS have the appropriate skills and are best placed to undertake this work although capacity and resource of their service needed to be considered.	Interviews
4.4	Using nationally produced leaflets had its place but there was merit in maintaining leaflets that outlined local procedures.	Interviews
4.5	There may not be sufficient support in place for patient information leaflet authors .	Case studies
4.6	The process described in a patient information policy may not reflect the reality.	Case studies
4.7	Having a documented process with an allocated patient information manager helps to give some visibility and governance to the production of good quality information.	Case studies (NTW)
5	Influencing	
5.1	Understanding what processes are in place already can assist LKS staff when making the case for using evidence.	Case studies
5.2	Building productive working relationships can take time but ultimately is key to the success of any influencing exercise.	Case studies
5.3	Highlighting the time saving element of using the library service to identify evidence for patient information will encourage staff to utilise our skills and make the process more efficient for others.	Case studies
5.4	Impending CQC inspection can be a good lever.	Case studies (Walsall)
5.5	Changes to the process or suggesting changes to the language used in leaflets can be challenging when influencing authors who were generally from clinical teams.	Interviews
5.6	Building on existing relationships was important; where an LKS had good links and was already seen as the "go-to" place for evidence generally	Interviews

	(for example, for clinicians' own use) this was often a stepping stone to having the opportunity to provide the evidence for patient information leaflets.	
5.7	It can take time to identify who is responsible for patient information and what processes are in place. Key people that it might be helpful to approach (if available) are: • Author(s) of a patient information policy • Patient Information Lead • Patient Information Group / Committee • Reading group • Patient Information Centre / Macmillan Hub • Communications team • Clinical Governance team • Quality Assurance team • Patient Advisory Liaison (PALs) • Chaplains	Case studies
5.8	It is important to think about how to demonstrate impact and cost/benefit of LKS providing this support.	Interviews
6	Literacy	
6.1	Health literacy is also a key component, and the link must be made between high quality information but also presenting it in a meaningful way and not assuming overly high levels of health literacy.	Case studies
6.2	Involving patients and carers can help to enhance patient information by ensuring it is written in plain language and understandable.	Case studies
6.3	LKS have a role in advocating the use of plain language.	Interviews