



Little Hearts Matter
Information Production Policy

Document Initiated: September 2022
Document Owner: Chief Executive and Information Administrator
Approved by: Trustees
Approval Date: September 2024
Review Date: September 2026

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Introduction

Little Hearts Matter is totally committed to producing high quality information in line with our strategic aims. The charity works to ensure that our information is accurate and accessible to users, and always strives to give a balanced view, for example by explaining different treatments of choice used in different hospitals. We are in the unique position of having access to the body of experience of our membership, families who live with the implications of these health conditions every day. This provides a reference point for the information need as well as a varied social and educational balance to our different information produced. We also have access to a team of medical experts.

We will conduct a mini review of all our information products each year before the strategic and budget planning process starts. This will include a plan for which documents need to be revised and reprinted during the year.

We will maintain records of all our publications, the process of producing them, and reviews and updates carried out.

Overarching responsibility for the charity's information process sits with the Board of Trustees. All policies are reviewed formally on an annual basis and are agreed at a Trustee meeting held in September.

What Information sits within the scope of our information production process

In scope

- All scripted medical and most lifestyle documents, for patients and their families, parents, and expectant parents.
- Produced in printed, web-based, online or any visual media format.
- Not the newsletter as a whole, but medical and lifestyle texts within it will be part of the scope of work once they have been printed as separate information sheets.
- Materials produced for different age groups of audience are included, according to the above criteria.
- Web pages on medical or lifestyle topics.
- During the three-year period, we plan to review all documents, medical publications every 2 years, Lifestyle publications as required.

Out of scope

- Lifestyle and general information where the information primarily involves signposting and is based on government policy and personal experiences and not medical evidencing.
- Telephone conversations, social media postings and online discussions are excluded from the scope of work, although references may be made to formal publications (printed and online) which are included in the scope of work.

The statement which is displayed on our social media sites is 'All user generated content on our Facebook page and on our closed member Facebook group is the views of individuals and does not represent the views, policy or advice of Little Hearts Matter

- Fundraising materials are out of scope.

On the Document Control spreadsheet, a column is included to specify whether a publication is within the scope of the Information Production Policy.

People involved

All those involved in producing information will be made aware of the requirements of the Patient Information Forum process. We are committed to making sure people acknowledge their understanding of our information policy and will maintain records of their acknowledgement of understanding.

People involved are the following:

- Head of Services
- Information Administrator
- Creative Designer
- Head of Youth Services
- LHM Adult Service Lead
- Child Support Lead
- Social media and Website Support Lead
- Trustees / Expert Users –
- Service User Reader Panel Groups – Parent, Adult, Youth.
- Medical Advisors and Authors –
 - Dr David Crossland MB cHB MRPCH
Consultant Paediatric and Adult Congenital Cardiologist at The Freeman Hospital
 - Dr Zdenka Reinhardt
Consultant Congenital Cardiologist, Transplantation at The Freeman Hospital
 - Amy Staite
Dietician at The Brompton Hospital

- Dr Anna Seal MB Bhir MD (res) MRCP
Consultant Congenital and Fetal Cardiologist at BCH and Birmingham Women's Hospital
- Dr Jo Wray
Child Psychologist and Researcher at The Institute of Child Health, London attached to Great Ormond Street)
- Dr Stephen Williams MBChb, FRCPCh, MSc Comm Child Health
Paediatrician at North Staffordshire NHS Trust
- Dr Paul Clift
Consultant Adult Congenital Cardiologist at Queen Elizabeth Hospital
- Dr Katherine Brown MB bChir MD (Res0 MRCP)
Consultant Paediatric Cardiac Intensivist at Great Ormond Street
- Dr Louise Coats
Consultant ACHD Cardiologist at the Freeman Hospital
- UCL Clinical Operational Research Unit - Christina Pagel, Sonya Crowe.
<https://www.ucl.ac.uk/clinical-operational-research-unit/research-domains/congenital-heart-disease-children-and-adults>

Abbreviations

RGN	Registered General Nurse
F & GP	Finance and General-Purpose Committee
BCCA	British Congenital Cardiac Association
RSCN	Registered Sick Children's Nurse
BME	Black and Minority Ethnic

Further charity member users will be identified as required for individual project planning, reviews and will be involved in reviewing materials prior to publication. They will also provide feedback and impact information post publication.

Contributors are chosen based on their knowledge and experience either as relevant professionals or as users of the service. In the unlikely event of any conflicts of interest, these would be declared in writing on the piece of information.

The charity will need to maintain an overall mix of skills between the office and volunteer team. These skills are all those required to create a piece of information, and include research skills, critical appraisal skills, copywriting skills and editing skills. This will be reviewed as part of the annual strategic planning process. Any gaps identified will be addressed.

Overall responsibility for producing information of the correct quality is held by the Chief Executive and the Board of Trustees.

Staff and Information Volunteer Awareness and Training

All members of staff are involved in the production of information so are introduced to the Patient Information Forum Tick aims, the LHM Information Process and the charity's Brand Guidelines as part of their Induction (a two-week process of introduction to the work of the charity. The aims and objectives of all areas of the charity's work and the processes involved in all areas of work)

Members of staff who will take a direct role in the production of information will spend time with the Information Team and will receive a more in-depth training with regards to the process and stages of information production, in line with the Information Production Policy.

All members of staff will look at the charity's processes annually as part of yearly staff training.

Principles - Target audience

Our primary target audience, for information projects, is defined by our governing document, which sets out the work we do as a charity.

We support a specific patient group and their families, who have unique information needs. These needs are due to their health condition, which is rare and complex, and the ongoing effects of those conditions.

Information produced by the charity will aim to inform

Age groups: Children aged 7–11 years, 12-14 years 14-17 years

Adults living with half a heart 18+ years.

Parents and other family members.

These principles are the promises we make when creating information. Our principles are the standards we follow to make sure all the information we create is trustworthy, easy to understand, fair, and respectful.

Our principles:

- **Accurate and safe:** We use trusted, up-to-date medical sources so people can rely on our information.
- **Clear and easy to understand:** We avoid medical jargon and explain things in plain language.
- **Fair and inclusive:** We respect different backgrounds, health needs, and experiences.
- **Supportive of informed choices:** We provide balanced information so people can make decisions about their health confidently.

- **Respectful of privacy:** We protect personal details and only share stories anonymously or with permission.

Information Development Process

How information needs are identified.

We are a user led organisation, and all information produced is generated as a direct response to user needs.

We regularly consult our members to identify new and changing information needs, and to help us prioritise potential new information projects. Their views will be sought informally during the support work we undertake daily but more formally through online and face to face surveys and general assessments of their priorities, within all age groups, at conferences and during workshops. Focussed reviews of need are conducted via social media questions and at face-to-face events.

Membership surveys are carried out biannually, and the results of these would also feed into future project planning. Member needs are also identified through enquiries to the support line, emails into the office, messages on the message boards, and questions on Facebook.

Our desired outcomes are to alleviate stress and reduce the isolation, fear and lack of understanding that comes with these conditions regardless of social position or educational level.

We also have several other audiences we seek to inform. These are professionals in fields such as healthcare, education, social services and government.

Healthcare professionals may also suggest areas where their patients would benefit from further support and information.

Information Project Planning

Information projects are planned as part of the service strategy in the autumn of each year: a project plan, which includes how the needs were identified, what information would meet that need and what format that information will appear in, is developed by the Service Team together with outline costs which are put to Trustees for approval as part of the annual budget cycle. This includes both plans for new materials and plans to update existing materials. *See Project Plan attached.*

These would all be ways of identifying information and access needs. Skills resourcing would be discussed at the planning meeting, with any relevant information from appraisal (such as training and development needs) being included in the planning. Any volunteer training required would be identified here as well.

- Information will be well designed, easy to read and easy to use, within the context of a complex health condition which means that some of the information to be communicated is complex and hard to understand.
- It will be produced to meet users' specific needs.

- Any access needs will be assessed and met.
- We will ensure independent trusted sources support the information.
- We will always include relevant alternative views.
- Draft projects will be tested with representatives of our target audience.
- Feedback from users will be recorded and used in continual improvement of information projects.
- We fund information projects in a variety of ways, but this will not be allowed to impact on the integrity of the information. Funding will be kept separate to information production and would never be accepted if any influence on content would be required. Any third parties who have an interest in an information product will be identified on the document, together with an explanation of their involvement.

Authorship

Having identified the need for a piece of information the charity will seek an appropriate internal/external author. The author will be asked to declare any conflict of interest (see author letter on page 16). If case studies, pictures or quotes are included, consent will be gained and documented.

We use an up-to-date team of medical advisors, made possible by our close links with expert medical teams. Please see 'PEOPLE INVOLVED'

We will ensure impartiality in our information, making sure that a range of treatment options are shown if applicable, and alternative views are always presented.

We have a list of approved experts who are all currently practising in their field, which will grow as we continue to develop new publications. These people are chosen as leaders in their field, and our list of authors and experts mirrors the set-up of congenital cardiac care in the UK. We will also continue to draw heavily on knowledge derived from the experience of patients and families, and professionals involved in the care of this patient group as relevant published information may not yet be available.

Authors will be tasked with selecting and applying evidence gained.

The experts selected would be noted on the individual project plan, together with the reason for inviting their contribution. They will be asked for their qualifications and sources of reference they have used – see 'Letter to Contributors' on page 16. Any other sources of evidence used will be included in individual project files and noted on the project plan. If relevant, a note of search terms would be included.

We will primarily be informing families about existing practice which may contain reference to research results. Existing and current practice has already been deemed to be the best way of approaching a particular treatment, it is highly unlikely that we would be proposing new or alternative treatments or therapies which are not part of an existing body of approved practice. We aim to provide a balanced account reflecting the weight of the available evidence and we will identify any uncertainties. Where there are differing views, advice from

the lead in that particular field would be obtained and our medical advisors would also be approached

Feedback from peer or authoritative or user review would go in the first instance to the Information Administrator who would log the feedback and pass it on to the author of the publication. The author would decide what to do with the feedback and respond to the reviewer accordingly. We will ensure that there is a trail showing the feedback, what decision is made, and whether that action has been carried out. Copies of feedback will be kept in individual project folders.

Approval

Information is then formally approved by the Head of Services (or designated lead) before production of publications

Assessment of the information production processes

A formal yearly review of the charity's information production process policy will be undertaken by the LHM Information Team, coordinated by the Information Administrator, to check that the processes are up to date and still relevant. The document is then presented to the Board for final approval. This is in line with the Little Hearts Matter Protocol and Process policy. Once the policy has been formally reviewed it will be agreed and dated during the September Trustee meeting. The policy will then be highlighted on the charity's website.

The process will also be reviewed by the LHM Information Team informally at the end of every information project.

PIF Assessment

These processes would follow the Patient Information Forum information requirements.

In year one and two of the Patient Information Forum tick assessment a full assessment will be made with the PIF team using their assessment process, aligned to the LHM Information Production policy.

User views

We have a process in place whereby users' views are sought at different stages in the development of a piece of information. User views are taken into account in the planning of new projects through discussions at the service team meetings.

We consult on content with members of our 'Reader Panels' – members of these panels are members (users) of the charity services who represent all areas of the Fontan Journey and non-members of the charity who have expertise in education, social care or employment. All charity members are offered an opportunity to comment on new information as they bring different experience to the process.

LHM has members from all socio/economic, ethnic and educational level back grounds. The LHM team know the membership well and can reach out to more difficult to reach members for their comments.

Congenital heart disease often goes hand in hand with educational deficits so information written for our child, teen and adult groups will be tested with those audiences. The charity seeks advice from organisation that specialise in writing information for people with difficulty access information.

Non-members who have a specific skill set would be asked to review an appropriate piece of information.

Members of the panel are sent a 'review questions' form to be used as a guideline and asks them to look at the written style, structure, content and presentation of the information and ensure that their information and access needs have been met. Comments are then forwarded to the author for consideration and changes are made accordingly and if deemed appropriate.

Part of the planning process will include the level of language and style of presentation used to explain the information. Different publications are created for different age groups so language must be appropriate and easily understood. Visualisation may be the preferred method of dissemination.

The language that a piece of information is produced in will also form part of the planning process, in line with user feedback in the planning stages of a new project. Experts in commonly sought languages will be refereed to for their expertise where needed.

Part of the Information Planning process would be to highlight the group that a particular information product would be created for and therefore tested by. For example – a piece of information that had been written for parents would be tested by parent members of the Reader panel who represent the right part of the Fontan Journey. The Information Team would work to identify parents from different backgrounds to ensure assess ability for everyone.

Child-centred information would be tested with representatives of their age group and the one above. Many of our young members have difficulty understanding information so testing a new product with a range of members is essential.

Sources and references

Sources and references will either be indicated on the finished product, or a statement will be applied saying 'references are available from LHM office on request'. This information will be filed in each individual project folder.

Filing system

We hold folders containing all relevant documents relating to an individual publication on the LHM server / SharePoint, with one folder per publication, plus an overall Information Production folder. We have a system of shared folders for use by office-based staff. We plan to keep documents for a minimum of five years. Implement an archiving process when necessary.

Project plan – for individual projects

Our project plan template provides further detail on the process used for developing information projects. It shows how we control each aspect of the process e.g., words, visuals and outsourced services. We have a section of the project plan, which is a checklist, to make sure that key areas of the Information Production are reviewed for each information project.

Outsourced services

External suppliers are chosen by considering their skill and expertise in the area, their experience, their ability to offer a competitive price, their ability to deliver on time, and whether they can empathise with the charity sector in general and the needs of our members in particular. We always obtain three quotations from different companies for comparison.

LHM AI Guidance for Publications

Purpose

Guide safe and ethical use of AI in creating, reviewing, and sharing publications.

Principles

- **Accuracy:** AI supports, not replaces, expert review.
- **Transparency:** AI use must be disclosed.
- **Ethical:** AI cannot replace human authors or patient voices.
- **Data Safety:** No confidential or sensitive patient data.

What AI Can Do

- Rewrite content in plain language.
- Improve accessibility (audio, translations, summaries).
- Help format or structure documents.
- Draft content for review (clearly marked).

What AI Cannot Do

- Give clinical advice without expert oversight.
- Fabricate references, sources, or data.
- Replace patient stories or lived experiences.
- Skip peer review or quality checks.

Risk Management

- Expert review and source verification for all AI content.

- Check for bias and fairness.
- Archive drafts clearly.
- Disclose AI use in publications.

Benefits

- Makes content easier to understand.
- Supports multiple formats (audio, large print).
- Tailors content to different readers.
- Frees staff for strategic work.

Risks

- Potential misinformation or oversimplification.
- Loss of trust if content feels “machine-made.”
- Possible bias or exclusion of groups.
- Privacy risks if sensitive data is used.

Conflicts of Interest

If an author, contributor or verifier declares a conflict of interest the Little Hearts Matter Information Team will discuss whether the conflict is relevant to the publication or the Little Hearts Matter position on a given issue. If the team agree that a conflict to the project is clear the authorship, contributions and or verification will be transferred to another person.

Declaration and Management of Conflicts of Interest

To maintain the integrity, impartiality, and credibility of LHM's health information, all individuals involved in the development, review, or approval of PIF Tick-accredited resources must declare any actual, potential, or perceived conflicts of interest.

What Constitutes a Conflict of Interest

A conflict of interest may arise where an individual's ability to make an impartial judgement is compromised, or could be perceived to be compromised, by:

- Financial relationships with commercial companies, sponsors, or suppliers.
- Personal or professional involvement with a treatment, product, or service referred to in the publication.
- Close personal relationships with individuals or organisations featured in the information.
- Dual roles within LHM or with external organisations that influence or benefit from the content.

- Undue influence arising from seniority, positional power, or organisational interests.

Declaration Process

- All contributors (staff, trustees, external reviewers, clinicians, lived experience partners) must complete a **Conflict-of-Interest Declaration Form** before participating in the development or review of any PIF Tick resource, if deemed necessary.
- Declarations will be reviewed by the [Information Lead], who will determine whether the conflict needs to be managed, mitigated, or whether the individual should be excluded from the process.

Management Actions

Depending on the nature of the conflict, the following actions may be taken:

- Full participation with declared interest recorded and monitored.
- Limited involvement (e.g. contribution allowed but not final sign-off).
- Removal from the process if impartiality cannot be assured.
- Inclusion of a statement of transparency in the resource if appropriate (e.g. "This guide was reviewed by X, who has declared a relevant interest in Y").

Record-Keeping

- All declarations and management decisions will be recorded and retained for audit purposes.
- The register of conflicts will be reviewed annually alongside the PIF Tick self-assessment.

References and Sources of Medical, Social and Educational Information

This list is to be reviewed annually by the Head of Service at the service strategy meeting in autumn.

Overarching sources

- Little Hearts Matter – has a repository of information written and verified for the audiences of its members.
- NICOR – National Institute for Cardiovascular Outcomes Research – national congenital heart disease audit website.

NHS Evidence

- National Institute for Health and Clinical Excellence (NICE)
- Children's Congenital Cardiac Services in England – Service Standards (agreed 23 July 2015)

- PubMed – for access to abstracts or papers about specific topics
- UCL – Clinical Operational Research for Congenital Heart Disease in Adults and Children. <https://www.ucl.ac.uk/clinical-operational-research-unit/research-domains/congenital-heart-disease-children-and-adults>
- Patient UK
- The Cochrane Collaboration
- Health Protection Agency
- Fontan Registry
 - Canada
 - USA
 - Australia and New Zealand

Journals

- **Cardiology in the Young**

This journal is devoted to cardiovascular issues affecting the young, and the older patient suffering the sequels of congenital heart disease, or other cardiac diseases acquired in childhood. The journal serves the interests of all professionals concerned with these topics. By design, the journal is international and multidisciplinary in its approach, and members of the editorial board take an active role in its mission, helping to make it the essential journal in paediatric cardiology. All aspects of paediatric cardiology are covered within the journal. The content includes original articles, brief reports, editorials, reviews, and papers devoted to continuing professional development.

This is a major LHM source of up-to-date thinking and peer reviewed practice relating to congenital heart disease.

- **Lancet**

The Cardiology & Vascular Medicine Collection

www.thelancet.com/collections/cardiology-vascular-medicine?collexcode=103

This publication is a major source of newly published and reviewed work and often an indicator for new practice.

- **British Medical Journal**

Helping doctors to make informed decisions.

www.bmj.com

Provides a general overview of medical practice, changes in the NHS and political decisions that may affect patient care.

- **Nursing Times**

A journal providing updates within nursing practice, clinical research, NHS and health care news, online nurse training courses and nurse specialist pages.

- **National and International Meetings**

LHM has access to national and international meetings.

Commonly attended are: -

- **British Congenital Cardiac Association Annual General Meeting**

Annual meeting held in the UK where advances in all areas of congenital heart disease are presented and discussed.

- **Birmingham Workshop Medical Meeting**

Annual meeting where complex congenital heart disease is explored from morphology, through diagnosis, treatment, lifestyle care and adult health issues.

[LHM attends this meeting annually to keep internal medical knowledge high and to create links with UK and world experts.](#)

- **British Cardiovascular Society Annual Meeting**

Annual meeting of all cardiac disciplines where NHS reform, cardiac advances and users' voice is available.

[LHM is a member of the Heart Care Partnership, one of the BCS affiliated groups so organises one of the speaker sessions and contributes to or attends other sessions.](#)

- **European and World Congenital Cardiac Congress**

Two meetings where European and global advances are presented.

[LHM's Medical Advisor attends on behalf of LHM. Many speakers from these international meetings also present at UK meetings.](#)

- **Congenital Cardiac Nurses Association Education Meetings**

Annual education days and a national conference where the care of patients with congenital heart conditions is discussed.

- **British Adult Congenital Cardiac Nurses Association.**

Annual education workshops and conferences where the care of adults with congenital cardiac disease is discussed.

- **Institute of Child Health Congenital Cardiac Meetings**

National and International meetings organised to explore global advances in the treatment and care of patients with congenital heart disease.

Author



[Date]

Dear

Re- [publication details]

Thank you so much for agreeing to write our [.....] parent information booklet.

Little Hearts Matter works with children and families affected by a diagnosis of a single functioning ventricle disorder. Our aim is always to offer our members support and information that helps them gain a greater understanding of their heart condition, its treatments and the lifestyle challenges that they will face.

It is very important to us that we are always able to demonstrate that we have the most up-to-date and accurate information available for our child and parent members which is why we turn to experts within the field to gain a professional view of our information resources.

As a charity we must be able to demonstrate how we have ensured the accuracy of our information and demonstrate that all possible treatment options are included as required. Would I be able to ask you when you have a moment to send me a list of references and evidence you will have sourced whilst writing the booklet please (for example, web references – page number, when they were accessed, an archive of what you may have looked at – for instances – this is what I searched on [date], the list I came up with – what I used and why. I have also attached an example of a list we were sent whilst writing the sports and exercise booklet.

Please could you declare if you have any conflict of interest or declare if you have none.

Please feel free to contact me if you have any questions or concerns.

Medical Verifier



[Date]

Dear

Re- [publication details]

Thank you so much for agreeing to review and edit our [.....] parent information booklet.

Little Hearts Matter works with children and families, affected by a diagnosis of a single functioning ventricle disorder. Our aim is always to offer our members support and information that helps them gain a greater understanding of their heart condition, its treatments and the lifestyle challenges that they will face.

It is very important to us that we are always able to demonstrate that we have the most up-to-date and accurate information available for our child and parent members which is why we turn to experts within the field to gain a professional view of our information resources.

As a charity we must be able to demonstrate how we have ensured the accuracy of our information and demonstrate that all possible treatment options are included as required.

We would therefore be grateful if you could read through the attached booklet and check for accuracy and consistency with current medical practice by looking at the sources used as well as the content of the booklet.

Please could you declare if you have any conflict of interest or declare if you have none.

Please feel free to contact me if you have any question or concerns.

With many thanks and best wishes from

Skills and resourcing

Charts at the end of this Policy document detail roles and responsibilities throughout the process of producing a piece of information, showing the pathway from idea to publication. This refers to staff, volunteers and external experts.

All members of staff have job descriptions, which include their roles and responsibilities in relation to information production, as relevant. They also included the skills which are essential and those which are desirable for the role. These would form a key part of induction for someone new to a role and are reviewed at annual appraisal. Any training needs would be identified at annual appraisal and recorded on a staff training record sheet kept in the personnel files.

During the annual planning cycle, we will identify the skills and resources needed to produce the planned information products. An important part of this will be to review the skills present in the organisation.

A Production Schedule is developed to ensure resourcing and workload can be managed effectively.

Signposting

Little Hearts Matter will signpost to expert information and other organisations who specialise in providing information about an aspect of medical care of lifestyle support or advice.

The Service and Information Teams will look for sources of support information that will enhance LHM's information and will seek advice regarding relevant and respected information from the band of experts highlighted above.

- Our medical experts will send on relevant research.
- Other charities will highlight new resources (which we will review).
- During research for a new publication, new sources of information will become apparent.

The authenticity, relevance, validity and accessibility of outside sources of information will be assessed and a record of why they have been used on LHM information will be highlighted as part of the information production process.

Layout and Design

We will produce our main medical and lifestyle documents in widely acceptable format, online and in hardcopy. As a rule, we will follow the guidance of the Plain English campaign for matters of language and design, following our branding guidelines. *See attached.*

The Little Hearts Matter logo will be used on all information produced by the charity and on our website, social media and any links used for video content.

Our design is carried out in-house, as part of the Creative Designer role and outsourced to relevant organisations or individuals. We follow LHM's Brand Guidelines document for all design work.

Diagrams / illustrations are an important element of our information production.

Photos – The charity uses lots of photos of children in real situations, with appropriate consent. The charity feels that it is better to use children in real situations as a better reflection of the needs of the LHM population. Care will be taken to be fully reflective of the LHM population and the UK-wide population. The project plan has a section on illustrations, which includes points such as copyright.

Presentation of difficult information and risks

Much of the information produced by Little Hearts Matter has to present difficult issues, parental or patient choices or outcome and survival risks. The charity works to ensure:

- That the information is accurate and can always be verified.
- That the language used to present complex and emotive information is clear and non-ambiguous, non-directional and that the charity always offers parallel support to the reader.

That visual aids are used as well as numbers to explain risk and outcomes e.g. we have used a journey to describe the outcomes for children with Hypoplastic Left Heart Syndrome. (Where numbers are used, if relevant, the opposite picture will also be stated, for example, if the risk of something is 10%, there is also a 90% risk of it not happening. Numbers will also be presented in different ways, for example 10% or 1 in 10.

Presenting Risk and Statistical Information

As part of our commitment to the PIF TICK principles, Little Hearts Matter ensures that all health information clearly and accurately presents risk and statistical data in a way that is meaningful, accessible, and appropriate for the intended audience — including adults, parents, children, and young people.

1. Use Natural Frequencies First

- Risk and probability information should be presented using **natural frequencies** (e.g. "3 out of 100") before any percentages or ratios.
- This supports clearer understanding and helps visualise real-world impact.
- *Example:*
 - ✓ "Out of 100 children who have this surgery, about 3 may need another operation."
 - ✗ "There is a 3% chance of reoperation."

2. Use Clear, Rounded Figures

- Avoid overly precise numbers (e.g. “9.7%”) unless clinically necessary.
- Use phrases like “around” or “about” to indicate reasonable rounding.
- Avoid ambiguous or subjective terms such as “low risk” without numeric context.

3. Ensure Balanced Comparisons

- When comparing risks (e.g. between treatments), ensure:
 - The same population and timeframe are used.
 - Context is clear and fair.
- *Example:*
“10 out of 100 children experience complications with this option, compared with 5 out of 100 for the alternative.”

4. Support with Visual Aids Where Appropriate

- For adult and parent audiences, use icon arrays or bar visuals to support interpretation of risks, especially where probabilities are very high or low.
- For child audiences, consider using relatable, illustrated examples (e.g. “Imagine 10 children in a room, and one...”) or age-appropriate infographics.

5. Tailor Language for Children and Young People

- Use plain, concrete language for all age groups, avoiding technical or abstract terms.
- Younger children benefit from simplified explanations and real-world analogies.
- Teenagers benefit from clear, direct information with practical relevance to them.
- *Examples:*
 - For younger children: “Most children feel sore after the operation, but nearly all feel better in a few days.”
 - For teenagers: “Out of 100 people, about 10 might feel sick after this. That means 90 won’t.”

6. Be Honest, Reassuring and Transparent

- Present risk in a supportive tone, especially in emotionally sensitive contexts.
- Where uncertainty exists, explain what is known and what isn’t.
- Always include context or actions that can reduce or manage the risk.

The full Service and Information teams work together to create the plan for the presentation of information to the younger audiences. Pictures and drawings are used to describe complex issues. Numbers are presented in visual as well as number form. Risks are presented in a clear but supportive fashion.

Films, cartoons, podcasts and animations are used to explain complex information. In some cases, the children, teenagers and young adults create the films with the LHM team.

Information Navigation

Little Hearts Matter uses many information media to ensure that information is easily accessible for anyone so that they can find the information and support they are seeking. The principle for online information is that the reader is only one or two clicks away from the information they are seeking.

At the beginning of every publication, in hard copy or online, there is a content list that allows the reader to seek the page or click directly to information that they are seeking.

Information Presentation

Part of the information production process is for the team to look at the style and medium to be used to gain the greatest useability, understanding and accessibility.

The formats that can be used are.

- Pictorial – a picture-led resources with minimal text or a voice over.
- Animation – following an animation that describes difficult medical information, allows readers/watcher to understand in visual stages complex pieces of information. The language can be changed depending on the audience.
- Summaries – brief easy-to-read summaries of a longer piece of text that sit at the beginning of a piece of information. This presentation allows the reader an opportunity to gain a short understanding of a longer text. They can then choose to read on if they wish.

Including Summaries in Longer Publications

- In line with the PIF TICK standard for clear and accessible health information, Little Hearts Matter includes summaries in longer publications to support comprehension, accessibility, and ease of use for all audiences.

When to Include a Summary

- A summary should be included when:
- The publication is longer than four printed pages or requires scrolling on more than two full screens online.
- The information covers multiple stages, topics, or options (e.g. diagnosis, treatment, recovery, emotional support).
- The content contains complex or emotionally demanding information where readers may benefit from key takeaways.

- The publication is intended for a mixed audience (e.g. families, children, professionals) and a quick overview helps each group decide whether and how to read further.
- The information is likely to be used in decision-making, so that users can quickly review their options and next steps.

What the Summary Should Include

- A well-designed summary should:
- Be placed at the start (executive summary) or end (recap of key points) of the publication.
- Use plain English and be no longer than 150–200 words.
- Highlight:
- The main purpose of the resource.
- The key points or messages.
- Any actions or decisions the reader may need to consider.
- Where to find further detail or support.
- Accessible Summary Options
- Depending on the audience, a summary may also be offered in:
- Bullet points for easier scanning.
- Visual formats (e.g. infographics, icons, timelines).
- Simplified or Easy Read versions, especially for younger readers or people with lower literacy.
- Longer text - will be used to explain complex information but presented in small sections with pictures and photographs added to illustrate what has been said.

Hard to Reach Groups

Diversity Equity and Inclusion

Single ventricle heart disease does not discriminate. It affects every social, ethnic, gender and religious group equally. As a UK-based organisation the charity is mindful of the need to ensure that all information is accessible to all areas of our mixed social and cultural community.

Little Hearts Matter has its own DEI policy - [chrome-extension://efaidnbmnnnibpcajpcgclefindmkaj/https://www.lhm.org.uk/wp-content/uploads/2023/09/DEI-2023.pdf](https://www.lhm.org.uk/wp-content/uploads/2023/09/DEI-2023.pdf)

All written or visual condition, treatment and lifestyle information is reviewed for accessibility by the different communities. The charity works to broaden the information reader panel and works to see focussed advice from a variety of communities as information is created.

Health Literacy - the ability of an individual to obtain and translate knowledge and information in order to maintain and improve health in a way that is appropriate to the individual and system contexts.

Explaining complex medical information sits at the heart of Little Hearts Matters work. To ensure that as many people as possible can understand our information the charity uses mixed media, set at different age and understanding levels e.g., some written text, some abbreviated text, some animated and voiceover presentation and some face-to-face explanation.

Digital Literacy - an individual's ability to find, evaluate, and communicate information using typing or digital media platforms. Although we live in a digital age not all people accessing information have the skill levels or desire to access information online. Little Hearts Matter works to reduce the need to travel far through the LHM digital media to find information. The information is presented in a variety of media, written animated, voiceovers, films and pictorial, all of which are available on handheld devices.

Supporting People with Low Digital Literacy or Limited Digital Access

At Little Hearts Matter, we are committed to making all our information accessible, inclusive, and available to everyone — regardless of their confidence with or access to digital tools. In line with the PIF TICK standards, we take active steps to support people with **low digital literacy** or **limited internet access** so they can understand and use our information effectively.

1. Ask and Offer Alternatives

- We always ask how people prefer to receive information, and we do not assume digital access or skills.
- If someone cannot easily access or navigate digital content (e.g. websites, PDFs, videos, social media), we offer appropriate alternatives.

2. Alternatives to Digital Formats

We provide a range of non-digital or supported formats, including:

- **Printed versions** of guides, factsheets, or resources by post.
- **Verbal explanations** from trained staff or volunteers over the phone or in person.
- **Simplified or Easy Read formats** for people who prefer minimal text or need extra clarity.
- **Support to access digital information**, such as:
 - Talking someone through how to use a webpage or document.
 - Emailing files in user-friendly formats (e.g. Word instead of PDF).

- Providing transcripts or summaries of video or audio content.

3. Inclusive Practice

- We ensure that no one is excluded from our information services because of digital barriers.
- We use plain English, avoid jargon, and test materials with diverse users to check usability across platforms and formats.
- We actively listen to what works best for each person and adapt our approach accordingly

Language – For some members, accessing information in English is difficult as it is not their native tongue. It is also important to remember that even if someone speaks English, medical terms are not in everyday conversation and when people are stressed, they revert to wanting to speak their comfortable first language.

The LHM team access different language specialists as required to produce information, in all types of media, in languages that ensures access for people of different nationalities settled in the UK.

Translation of Patient Information

1. Audience Needs

We identify communities needing translations to make information accessible to those with limited English and diverse cultural backgrounds.

2. Translation Process

Qualified translators use clear, simple language while accurately translating medical terms.

3. Quality Check

Translations are reviewed through proofreading, bilingual checks, and feedback from patient groups to ensure accuracy and cultural sensitivity.

4. Cultural Adaptation

Resources are adapted to respect cultural values and health beliefs, while keeping medical guidance accurate.

5. Accessibility

Translations are available in print, digital, audio, and Easy Read formats to meet patient needs.

6. Review & Improvement

Materials are updated regularly, and patient feedback is used to improve translations.

Conclusion:

Our approach ensures patient information is **reliable, inclusive, accessible, and culturally sensitive**, supporting fair access to healthcare.

Information for children, teenagers and adults with learning difficulties.

Congenital heart disease often goes hand in hand with educational deficits so information written for our child, teen and adult groups will be tested with those audiences. The charity seeks advice from organisation that specialise in writing information for people with difficulty accessing information.

- Government information <https://www.england.nhs.uk/wp-content/uploads/2018/06/LearningDisabilityAccessCommsGuidance.pdf>
- Making information accessible Change People - <https://www.changepeople.org/getmedia/923a6399-c13f-418c-bb29-051413f7e3a3/How-to-make-info-accessible-guide-2016-Final>

Information production and review

Documents will be reviewed on a regular basis and if required they will be archived if they are to be withdrawn from circulation.

Review dates will be set at the project planning stage for each individual piece of information.

We will conduct annual reviews of publications where the information changes frequently, for example vaccination information.

Medical texts will be reviewed every two years and lifestyle texts on a three-yearly basis.

If there are no changes to the information reviewed no formal updates will be required. The two-year cycle for review will continue but at eight years from original publication all medical documentation will be rewritten and new as well as existing sources of information will be sought.

This cycle is indicative, and any publication can be reviewed whenever necessary.

We have a Document Control spreadsheet, which is kept by the Information Administrator.

A master copy of each publication, and all supporting documents and correspondence will also be kept.

Source data needs to be archived.

All project files will be kept for at least five years.

All Little Hearts Matters policy and process documents are reviewed annually in August and then presented to the Board of Trustees for recorded agreement at the September Trustee meeting. All policies are available to members and interested parties on the Little Hearts Matter website.

The date of the information production and the planned date of review will be added to each document, hard or digital copy. The dates for updates will be updated once each review has taken place. These dates will also sit on the Information process chart which will be managed by the Information Administrator.

Archiving

Archiving Responsibility

- The [named role, e.g. Information Lead] is responsible for archiving all finalised and superseded PIF Tick publications.
- This includes printed materials, digital PDFs, web content, and co-produced resources.

2. Archiving Criteria

- Publications must be archived when:
 - A new edition is released.
 - The content becomes obsolete or is withdrawn.

3. Version Control

- Each archived version should be clearly labelled with:
 - Title
 - Version number or date of publication
 - Date archived
 - Reason for archiving (e.g. updated, withdrawn)
- Ensure filenames follow a consistent naming convention:
Title_VersionDate_ArchivedDate_Status.pdf
(e.g. *TransplantGuide_May2024_15July2025_Withdrawn.pdf*)

Dissemination

The Little Hearts Matter team will work to disseminate the information created across all user groups using a series of awareness tools.

1. Social Media.
2. LHM Newsletters.
3. Information held in hospitals.
4. Promotion of online resource libraries.
5. Where possible through other media, national news, online, TikTok, podcasts, focussed media.

The team will work to raise awareness of the information resources available within medical, educational, social service, third sector and governmental information arenas.

Evaluation and Impact

User focussed feedback will be sought at every stage of the information production process and will inform the building of a new information tool and the edit and review process. The charity aims to ensure that user feedback is obtained from a variety of different social, ethnic and religious groups to ensure that all the charity's information resources are equally available.

Post dissemination, formal feedback, on any information tool, in any medium will be sought formally through surveys, via our extensive following on social media and informally at events and one-to-one and group support forums.

Data on the number of downloads a piece of information has had and the number of written pieces of information that have been sent out will also be collated.

Members using online information can add feedback on a publication to the website or via the information sources accessed on phones or tablets.

Professionals will also be asked to report on the information tools and will be asked to feed back any thoughts about the impact that the information tools may be having.

Formal research about the impact of a specific information tool may be implemented. For example, an information tool created for child or teen members may undergo a pre- and post-use survey.

Setting outcome goals

It will be possible to set small outcome goals if we are working to formally review a specific product but some of our information is sent at a time of very high stress so assessing impact will be emotionally compromised. We will set outcome goals at the beginning of each project. These may not be numerical but may instead be about ensuring the relevant member group are aware of a particular publication. We can track click-throughs following social media posts as well as the number of hard copy publications sent out to both members and medical professionals.

We are implementing a questionnaire that users will be able to access via QR code to capture qualitative data. This QR code will be sent out with all physical information.

Any numerical goals we set in terms of distribution / download of an information product will vary greatly by booklet as different publications are relevant for different numbers of our membership.

Outcomes, Targets and Evidence for a Single Resource

Resource Title: *Your Child's Heart Surgery: What to Expect*

Audience: Parents and carers of children with single ventricle heart conditions

Format: 16-page printed and downloadable PDF guide

Publication Date: January 2024

Review Date: January 2026

Intended Outcomes

1. Increase parent/carer understanding of the stages and risks of heart surgery for children with SVH.
2. Help families feel more prepared and less anxious in the lead-up to surgery.
3. Improve families' ability to ask questions and communicate with clinical teams.
4. Offer reassurance through shared experiences and clear explanations.

Targets

Target	Measure	Goal
1. 80% of readers report improved understanding after reading the guide	Post-use feedback survey	≥ 80%
2. Guide is downloaded/shared at least 500 times in first 12 months	Website and email analytics	≥ 500 downloads
3. Resource is rated as "useful" by at least 90% of respondents	User rating in feedback forms	≥ 90% "useful"
4. Resource is endorsed by two clinical reviewers	Signed reviewer approval forms	2+ endorsements

Evidence Outcomes Were Met

- **User Feedback Survey (Feb–Oct 2024):**
 - 87% of 54 respondents reported improved understanding of surgery stages.
 - 92% said the guide made them feel more prepared.
 - 94% rated the guide as "useful" or "very useful."
 - Comments included:
"It helped me know what to expect — I felt more in control at the hospital."
"The photos and family quotes made a big difference."
- **Analytics:**
 - 713 downloads from the website and email campaign in the first 9 months.
 - 86 physical copies distributed via clinical partners and events.
- **Clinical Endorsement:**
 - Reviewed and approved by two paediatric cardiologists (Dr X and Dr Y) and one specialist nurse.
 - Review forms signed and stored on file.

Compliments, Comments and Complaints

Little Hearts Matter will happily take compliments or comments on any information resource created. The compliments will be recorded on the Information production report and stored in the allocated resource file.

Any comments about information that could be included in a future document or information that may highlight the need for a swift update will be recorded on the publication report sheet but will also be highlighted to the information team.

Any queries or complaints about the content of a specific publication would in the first instance be referred to the Information Administrator, who would then seek clarification regarding the issue from Chief Executive / Services Lead, who may refer to one of our medical advisors.

This would be recorded on the incident log.

The reason for any non-conformity would need to be established e.g., whether it was due to a change in medical practice or whether we may need to change our processes.

The Trustee responsible for information would be informed.

All comments on an information product will be collected and added to the data review.

There are several different levels of possible corrective actions to be taken, which would be proportionate to the level of the complaint / non-conformity and would involve a risk-based assessment. These could range from a sticker or insert within a pack, to withdrawing or reprinting a publication, together with proactively offering support to members who might have been misinformed.

The Chief Executive and Trustee responsible for information would agree the process to follow in each individual case and would determine who would be the correct expert to re-verify the information. Their authorisation would be needed prior to re-releasing the information.

The Chief Executive/Service Lead will communicate the outcome with the person who initially raised the concern.

We are actively seeking feedback from member families when we send out an information booklet and through feedback buttons on the charity website at the end of each information section. All comments requiring an action by LHM will be captured by the Information Administrator in the incident log.

A note will be made of whether action is needed, what action is taken, and when the matter is considered closed i.e., when no further action is required.

Compliance with all applicable UK legislation on data protection, promotion of medicines, and other relevant industry regulations.

Data Protection (UK GDPR & Data Protection Act 2018)

- All personal data included in or associated with are processed in accordance with the **UK GDPR** and the **Data Protection Act 2018**.
- Access to personal data is strictly limited to authorised personnel and protected through secure systems.
- Data retention and deletion policies are followed in line with statutory obligations.

Regulatory & Industry Compliance

Through these measures, we ensure that the information remains a reliable, accurate, and fully compliant reference for UK regulatory authorities and stakeholders.

Process chart

	NOTES / COMMENTS	
Name of Publication / Project		
<i>Define Project</i>		
New publication? Updated publication?		
How was the need identified for publication –Survey (link to source), Face to Face, Support Line, emails to office, Healthcare Professionals, In-house knowledge		Actioned by: Date: Information Stored:
Project Plan		Actioned by: Date: Information Stored: S:\O - P\PUBLICATIONS 2022
Aims and objectives for publication		Actioned by: Date: Information Stored:
Target audience		Actioned by: Date: Information Stored:

Illustrations / photos required		Actioned by: Date: Information Stored:
Photo permissions - How gained Where stored		Actioned by: Date: Information Stored:
Consent for studies, pictures and quotes (link source)		Actioned by: Date: Information Stored:
Appointed author		Actioned by: Date: Information Stored:
Name		
Contact Details		
Reason for appointing named Author Qualifications / Skills i.e. research (link to source)		Actioned by: Date: Information Stored:
Author letter sent (link to source)		Actioned by: Date: Information Stored:

Conflicts of interest: Yes / No – details if yes (what constitutes a conflict of interest)		Actioned by: Date: Information Stored:
Details recorded in Information Risk Register		Actioned by: Date: Information Stored:
Medical / Professional Verifier Name Why chosen Qualifications		Actioned by: Date: Information Stored:
Illustrator Name		Actioned by: Date: Information Stored:
Editor Name		Actioned by: Date: Information Stored:
Reader Panel Review Name Why chosen		Actioned by: Date: Information Stored:

Proof-reader		Actioned by: Date: Information Stored:
Consent for studies, pictures and quotes (link source)		Actioned by: Date: Information Stored:
Sources		
References		Actioned by: Date: Information Stored:
Research		Actioned by: Date: Information Stored:
Timeline for the Project		
Design and layout		Actioned by: Date: Information Stored:
Writing / creating format		Actioned by: Date: Information Stored:

<i>Final Production</i>		
Costing and Timeline		Actioned by: Date: Information Stored:
Obtain final production costs Proofread Final changes Sign off by Chief Executive F&GP sign-off final costs		Actioned by: Date: Information Stored:
Sign off for print. PDF to upload to website		Actioned by: Date: Information Stored:
<i>Verification/ Assessment Process</i>		
Medical / Professional verification		Actioned by: Date: Information Stored:
To author (edit)		Actioned by: Date: Information Stored:
Reader Panel		Actioned by: Date: Information Stored:

To author (edit)		Actioned by: Date: Information Stored:
Editor		Actioned by: Date: Information Stored:
Plain English Review		Actioned by: Date: Information Stored:
To author (edit)		Actioned by: Date: Information Stored:
Proof-reader		Actioned by: Date: Information Stored:
Author & team for final sign off		Actioned by: Date: Information Stored:
<i>Dissemination</i>		
Circulate to members		Actioned by: Date: Information Stored:

Circulate more widely e.g., medical professionals, press launch if relevant		Actioned by: Date: Information Stored:
Feedback from (positive/negative) • reader panels • users • documented (S:\O-P\Publications 2022 Incident Log) • social media		Actioned by: Date: Information Stored:
Issues reported to:		Actioned by: Date: Information Stored:
Review date:		Actioned by: Date: Information Stored:

Tick and Date	
	Needs of diversity and target audience are met
	Consistent and up-to-date clinical evidence and research
	Clear distinction between opinion and evidence-based information.
	Sources of evidence are clearly indicated
	User feedback sought and included where relevant
	Medical review carried out
	Date information is issued and planned review
	Possible / Alternative Treatment / care options are clearly presented/stated
	Clear aims and purpose of document – communicated
	Presented in the appropriate format for specified audience
	Any conflicts of interest declared
	Consistent layout and style guide followed
	Plain English review and medical terms explained where necessary
	Navigation aids e.g. contents lists, search facilities, indexing
	References included or statement 'references can be obtained from LHM'
	Publication and review date included
	Acknowledgements
	Funding references

	Proofread
	Written approval received from Author for final version
	Sign off for print • File to printer • Printer proof • Final sign off by Author • Final sign off by Chief Executive
	PDF produced for website

CHECKLIST

Appendix – language section

Inclusive Language Guidance Table (for PIF Tick Compliance)

Avoid Using	Use Instead	Reason / Notes
Patients	People with single ventricle heart (SVH) conditions / Children and young people with SVH / Families affected by SVH	Emphasises person-first language and recognises the full identity beyond medical status.
Sufferers / Victims	People living with / affected by SVH	Avoids framing people as helpless or defined by illness.
Parents	Parents and carers	More inclusive of non-parent caregivers (e.g. grandparents, guardians).
Normal (e.g. normal child)	Typically developing child / Other children / Children without SVH	“Normal” implies people with conditions are abnormal or deficient.
Handicapped / Disabled person	Person with a disability / Disabled person (if identity-first is appropriate and preferred)	Use with sensitivity — default to person-first unless individual or group prefers identity-first.
The elderly	Older adults / Adults aged 65+	“Elderly” can be patronising or vague — be specific where possible.

Avoid Using	Use Instead	Reason / Notes
He/she (as a default)	They / The child / The person	Use gender-neutral language unless referring to a specific individual.
Compliance (e.g. treatment compliance)	Engagement with treatment / Treatment choices	“Compliance” can feel judgemental; focus on collaboration and agency.
Case (e.g. medical case)	Person / Individual	Avoid reducing someone to a clinical subject.
Disease / Disorder (where not clinically necessary)	Condition / Health condition	“Disease” may sound severe or stigmatising — use only when medically accurate.

Usage Notes

- **Tailor terminology to the audience — e.g. “young people with SVH” for youth-facing materials; “families affected by SVH” in family guides.**
 - **Always use person-first language unless a group has expressed a preference otherwise (e.g. some disabled communities prefer identity-first language).**
 - **When in doubt, test language with members or ask how they prefer to be described.**
-