



C. Information Production System

C.5.1

The aim of our information production system, and purpose of information being produced, is to provide sufficient, reliable and up-to-date source of information for all those concerned with ALD and AMN including patients, families, carers and medical professionals. Information shall be evidence-based and user-focused - the need of our target audience should be clearly reflected in our information product. Information shall be obtained from current medical sources, or our medical advisers, but where there is a variance in opinion, and specific advice needs to be taken, we will ensure that all information is included, and that differing opinions are covered.

All information products are to be regularly reviewed, and updated as necessary, on an annual basis, and shall be fully accessible for the public on our website, with hard copies being sent to members, and made available on request.

Information is produced in response to the needs, requirements and arrangements of our target audience. This may include information on the condition, symptoms, treatment available and rights' of patients in terms of social and community health services (i.e. benefits, special education needs, counselling).

We have identified two target audiences for our information:

1. Patients & Families – to ensure good quality information is made available for patients and families – to improve the number of patients and families able to make informed decisions for them or their child when receiving diagnosis of ALD or AMN.
2. Health & Social Care Professionals – to ensure good quality information is made available to health and social care professionals – to improve the number of individuals in the health and social care profession being able to deal with a patient diagnosed with ALD or AMN appropriately.

C.5.2

Please see 'Information Production Process' [C:\Documents and Settings\ALD Penge\My Documents\ALD Life\Information Standard\C. Information Production System\Information Production Process.doc].

Please also see 'Information Production Process Handbook' [C:\Documents and Settings\ALD Penge\My Documents\ALD Life\Information Standard\C. Information Production System\Information Production Process Handbook.doc].

C.5.3

All documents relating to the information production system including our Information Production Process document is subject to document control. This is to ensure that we are able to review and make changes to our information production



process, systematically and efficiently. Please see 'Master Document Control' [C:\Documents and Settings\ALD Penge\My Documents\ALD Life\Information Standard\C. Information Production System\Master Document Control.doc].

All documents relating to the information production system also have footers outlining the document version and creation date.

A document control is also in place for documents needed for individual information products such as the Information Production Checklist. This is to ensure these documents take into account any changes to our Information Production Process. Please see 'Master Document Control' [C:\Documents and Settings\ALD Penge\My Documents\ALD Life\Information Standard\C. Information Production System\Master Document Control.doc].

All documents are reviewed on an annual basis to ensure its suitability to our Information Production Process, and require signing off by the CEO, Sara, and the Board of Trustees.

C.6

Due to the nature of our organisation, our target audience are primarily patients and families affected with ALD and AMN. We have identified health and social care professionals as part of our target audience because of the nature of the condition – both ALD and AMN are rare genetic disorders – and information required to deal with patients diagnosed with ALD or AMN isn't always easily accessible or reliable. We consulted with medical professionals, and found that the majority of medical professionals such as doctors, GPs and nurses had a lack of appropriate knowledge of ALD and AMN to effectively care or support patients affected by the disorder.

For each information product, a specific profile of the target audience, specific needs for that target audience, and specific arrangements such as resources to fulfil such needs are researched, and if necessary recorded, monitored and evaluated within the information production process.

C.7

ALD Life ensures that all information is well-designed, easy to read and usable by our target audience by consulting them throughout the information production process. Please see 'Information Production Process' [C:\Documents and Settings\ALD Penge\My Documents\ALD Life\Information Standard\C. Information Production System\Information Production Process.doc].



This is to ensure that all information products reflect the needs, requirements and arrangements of the target audience in terms of design, readability and usability.

We will follow best practices and principles where required. This involves researching and recording similar information products by scanning print products, or taking print screens of online products. We then assess the information products, and adopt best practices and principles, in line with our target audience's needs, requirements and arrangements. This is to ensure that we are also able to keep updated with best practices and principles in the production of information materials.

Thus far, we have identified that information that is clear and concise is appropriate to our target audience and their needs, requirements and arrangements through feedback from past focus groups. All current information products have clear headings and sub-headings, ensuring navigation through information products is easy. Information products are free from jargon, as many patients and families have little or no scientific knowledge, and where any jargon is included, they are clearly defined. Useful websites relating to information is provided for users to gain a more in-depth understanding of that particular area – in particular for health and social care individuals dealing with patients, who may require in-depth medical information.

We have currently identified that all information products should use visible and clear fonts, ideally Calibri, as we have identified it to have better visibility. We have also identified that all information should be written in size 12 fonts for online products, and size 10 fonts for print products, and all headings should have size 16 fonts. Backgrounds and banners should ideally use a blue or yellow colour that matches our logo, or a light colour to ensure it is user-friendly, and where necessary both. There should also be no high or low contrast and brightness, to ensure that the information products are readable and usable for all users. Please see 'Formatting Guide' [C:\Documents and Settings\ALD Penge\My Documents\ALD Life\Information Standard\C. Information Production System\Formatting Guide.doc].

All information products after being developed go through several focus groups consisting of patients, families, carers, medical specialists and unconnected individuals. The Fundraising and Business Development Manager gathers and records feedback from these to make continued improvements to information products, and our own practices and procedures, ensuring they, and future information products are as user-focused as possible.

He/she also gathers and records feedback sent by email, telephone and social media by the target audience after the information product has been approved and released. This is to ensure we are able to make continued improvements to information products throughout the information product's life cycle.



To further show our commitment to the production of information, our ALD Life logo has been copyrighted and trademarked. This is to ensure we are able to protect the ALD Life branding and logo from potential infringement, and clearly distinct ALD Life's information products.

C.8

We involve our service users in the production of information by:

- sending them an email to start an initial discussion about the information product including gathering feedback on their needs, requirements and arrangements e.g products in different languages etc
- organising various focus groups consisting of our target audience including patients, families, carers, medical professionals and unconnected individuals to make continued improvements to our information products, and make our information products as user-focused as possible. Focus groups have been identified to be best no bigger than 20 people, and must include individuals from a wide range of backgrounds in terms of experience dealing with the disorder including unconnected individuals.
- sending final draft versions of our information product by email to members including patients, families and medical professionals to collect and record their feedback. This is done through our contact database, e-tapestry.
- collecting and recording feedback sent by email, telephone and social media, which are monitored and evaluated along with all other feedback, and where applicable any updates to information products are made appropriately, and in line with our information production process. Please see 'Information Production Process' [C:\Documents and Settings\ALD Penge\My Documents\ALD Life\Information Standard\C. Information Production System\Information Production Process.doc].

C.9

ALD Life is committed to sourcing the best available evidence from reputable sources. As such, we use The Specialist Libraries of NHS Evidence, which include access to the following resources:

- The Cochrane Collaboration (<http://www.cochrane.org>), which provides up-to-date information about the effects of healthcare interventions
- Clinical Knowledge Summaries (<http://www.cks.nhs.uk>), which is an NHS-funded resource that provides information about common conditions
- National Institute of Health & Clinical Evidence (<http://www.nice.org.uk>)
- Health Technology Assessment (<http://www.hta.ac.uk>)
- The Campbell Collaboration (<http://www.campbellcollaboration.org>), which provides systematic reviews on social welfare



When sourcing information, we also have a list of recommended websites and publications we use including:

- Society for Endocrinology (<http://www.endocrinology.org>)
- Children living with Inherited Metabolic Disorders (<http://www.climb.org.uk>)
- Genetic Alliance UK (<http://www.geneticalliance.org.uk>)
- Orphanet Journal of Rare Diseases (<http://www.orld.com>)
- MedLine Plus (<http://www.nlm.nih.gov/medlineplus/medlineplus.html>)
- X-ALD Database (<http://www.x-ald.nl>)

Please see 'List of Useful Sources' [C:\Documents and Settings\ALD Penge\My Documents\ALD Life\Information Standard\C. Information Production System\Sources>List of Useful Sources.doc].

We are also given recommended publications and medical papers from our medical advisers and research volunteer. Please see 'Sources' folder.

A medical adviser is also responsible for signing off our list of recommended sources.

In the circumstance that there are no sources of evidence, for example for new treatments such as gene therapy, we will source evidence from our medical advisers. Any sources of evidence from a medical adviser will be checked by another medical adviser.

However, priority is given to sourcing evidence from our list of recommended sources, and medical advisers will only be sourced if there are no available sources on the subject matter.

Any unknowns and uncertainties, such as the effect of certain treatments on patients will be clearly outlined in information products.

To ensure that our information product is produced according to an explicit evidence-based process, we:

- Formulate key questions that need answering
- Identify the types of research that would best answer our questions (Randomised controlled trials, harm studies, patient and family experience, clinical expertise etc)
- Identify the key sources of evidence to search
- Devise search strategies for each sources of evidence
- Outline the inclusion and exclusion criteria for selecting evidence from our searches
- Appraise the evidence selected

We record all details including search terms used to search each sources of evidence and search dates. Please see 'List of sources form' [C:\Documents and Settings\ALD



Penge\My Documents\ALD Life\Information Standard\C. Information Production System>List of sources form.doc].

We also maintain an archive of information sources for each information product. Please see 'Archive of sources' [C:\Documents and Settings\ALD Penge\My Documents\ALD Life\Information Standard\C. Information Production System\Archive of sources.doc].

A full list of references will be displayed within our information product including a URL for the website, and phone number and email address if available. They will additionally be available to members of the public upon request. Our Information Products will state:

"Sources of evidence are available to the public upon application. Requests can be made by email to info@aldlife.org or telephone to 0208 473 7493"

Finally, when sourcing evidence, we ensure we use a wide range of resources as possible to look for alternative views and differing opinion, and only include information that is protocol for the ALD and AMN condition by consulting with patients, family representative and medical specialists via focus groups, and checking it with our medical advisers. All feedback are also recorded and monitored. Please see 'Feedback log' document [C:\Documents and Settings\ALD Penge\My Documents\ALD Life\Information Standard\C. Information Production System\Feedback log.doc].

These are then evaluated, and used to make continued improvements to our information product in line with our Information Production Process. Please see 'Information Product Process' [C:\Documents and Settings\ALD Penge\My Documents\ALD Life\Information Standard\C. Information Production System\Information Product Process.doc].

C.10

ALD Life ensures that all information is accessed from or supported by reliable, up-to-date and independent sources. We also ensure where there are alternative views and differing opinion, that all information is included.

All information included in our information products such as symptoms, treatments, social care and benefits are checked by our medical professionals, and through patients and families feedback of personal experiences, both help to ensure they are the protocol for the ALD and AMN condition.

We ensure that information doesn't come from individuals with an interest in an information product through sponsorship or advertising by carrying out conflicts of



interest checks, and making sure all those involved in the production of information sign our Conflict of Interest Statement. Please see 'Conflict of Interest Statement' [C:\Documents and Settings\ALD Penge\My Documents\ALD Life\Information Standard\C. Information Production System\Conflict of Interest Statement.doc].

In circumstances that conflicts of interest occur, these will be recorded in the information production process, and discussed in a meeting between our CEO and Board of Trustees.

Differences in opinion, and alternative views highlighted by patients, families or medical specialists at focus groups, or Board of Trustees and medical advisers during meetings are recorded and managed by our CEO, Sara. Please see 'Conflict of interest log' [C:\Documents and Settings\ALD Penge\My Documents\ALD Life\Information Standard\C. Information Production System\Conflict of Interest log.doc].

The CEO will then be responsible for deciding how each of these should be represented in the information product.

ALD Life doesn't intend to work with any sponsors or advertisers in the future. But, will ensure that all third party interests in our information products are clearly stated. Our Route Map currently clearly states:

"This work is part of the Route Maps for Rare Conditions project, facilitated by Genetic Alliance UK and funded by the Department of Health in England."

C.11

We currently feel that we have the right skills necessary to meet the workload of our information production system. However, we are always looking to develop and improve the skills of our workforce by looking at training and developing our staff and volunteers, internally or externally. All staff and volunteers, as part of their job description, are able to undergo a wide range of training and development. Training records are kept, with feedback and notes from staff and volunteers, to help us review external training, and record and pass on essential skills and knowledge. Please see 'Training & Development feedback form' [C:\Documents and Settings\ALD Penge\My Documents\ALD Life\Information Standard\C. Information Production System\Training & Development feedback form.doc].

Our Board of Trustees and medical advisers contribute their vast experience and expertise as well. All our Board of Trustees are affected directly by either ALD or AMN, either personally or within their families, and as such have an intimate knowledge and expertise of the condition. We have three specialist medical advisers who directly work with patients and families with ALD, AMN or both, and have



specialist knowledge and insight into relevant areas such as bone marrow transplant, metabolic diseases and genetic disorders. As such, our Board of Trustees and medical advisers offer a wide range of experience and expertise, and can provide feedback not only on our information materials before being released, but also help us in the production stages too – i.e research, writing.

Both staff and Board of Trustees attend conferences and meetings relevant to our organisation, attend events associated with partner organisations (ALD-AMN Global Alliance, Genetic Alliance UK), and through links with partner organisations receive regular newsletters and publications. Staff and Board of Trustees are also kept updated with the latest breakthroughs and news through mailing lists, trusted news sources and health discussion groups (HealthUnlocked).

Thus, we are generally well aware about new developments and changes relevant to ALD or AMN, before they become routinely acknowledged by patients and families, and are able to make amendments to our information products effectively.

C.12

All our information products are listed for review in May next year, apart from our Patient Information section of our website, which is due for review in March next year. No new publications are being planned at the moment. Our practical information leaflets are still to be printed and distributed. Please see 'Information Products Document' [C:\Documents and Settings\ALD Penge\My Documents\ALD Life\Information Standard\C. Information Production System\Information Products Document.doc].

When a need to publish an information product is identified, we record details including a information production process checklist, copies of research documents, draft versions and feedback in its separate folder in the 'Planned Information Products' folder. It will then be discussed by our CEO and Board of Trustees, who then decide on approving the product. If approved and upon completion, all files are then transferred to the 'Current Information Products' folder.

Any information products taken out of circulation permanently are stored in the 'Archive Information Products' folder, which is then reviewed for deletion after five years from the time taken out of circulation.

C.13

New information products, or clarification on a particular subject, are only considered when a particular need or requirement has been identified, or where ALD Life is aware of a certain breakthrough or development that our target audience



should be aware of, such as a new treatment or a cure for the disorder. In these circumstances, the Fundraising and Business Development Manager records and assesses each of these needs or breakthroughs, where it will be discussed by our Fundraising and Business Development Manager, CEO and Board of Trustees. Please see 'Needs and breakthrough log' [C:\Documents and Settings\ALD Penge\My Documents\ALD Life\Information Standard\C. Information Production System\Needs and breakthrough log.doc].

If a need to publish information is required, we update existing, or create new information products in line with our information production process. Please see 'Information Production Process' [C:\Documents and Settings\ALD Penge\My Documents\ALD Life\Information Standard\C. Information Production System\Information Production Process.doc].

Resources to fulfil the requirements of unplanned products are sourced from our charity reserves. See 'Reserves Policy' [C:\Documents and Settings\ALD Penge\My Documents\ALD Life\Information Standard\C. Information Production System\Reserves Policy.doc].

C.14

ALD Life is committed to not use any third party information sources in the production of information. This is to ensure our information production process is both as efficient as possible, and avoid potential conflict of interests. We also feel we have the required skills in our workforce to meet the requirements of our information production system, and are fully committed to ensuring our workforce is able to continue to meet these requirements by emphasising on training and developing our workforce, and avoid using third party information sources.

However, in the circumstance we feel that a third party information source such as a writer or editor is required, the Fundraising and Business Development Manager is responsible for thoroughly researching, analysing and evaluating third party information sources and their suitability to the production of the information material such as their skills, resources and expertise. He/she will be responsible for researching and interviewing a number of different third party information sources before recruiting the final candidate.

They will have to have a particular skill, resource or expertise that helps meet a particular need, requirement or arrangement of our target audience for example, an ability to create information products in multiple languages for patients and family representatives from different countries. We will always look to see if we have the particular skill, resource or expertise before looking at third party information sources.



Resources required to recruit a third party information source will be obtained, either by seeking funding or sourcing funds from our charity reserves. See 'Reserves Policy' [C:\Documents and Settings\ALD Penge\My Documents\ALD Life\Information Standard\C. Information Production System\Reserves Policy Statement.doc].

The CEO and Board of Trustees consider implications of using such a source on our organisation in terms of ensuring requirements of the Information Standard are met, and approve and sign off any third party information sources. If then, any third party information source is approved, they firstly have to be aware of, and acknowledge our policy statement and information production process, which is recorded in our record of policy acknowledgement spreadsheet. Please see 'Record of Policy Acknowledgement' [C:\Documents and Settings\ALD Penge\My Documents\ALD Life\Information Standard\A. Policy Statement\Record of Policy Acknowledgement-Version 1.xls].

The third party information source also has to pass conflict of interest checks, and have to sign and acknowledge our conflict of interest statement. These are recorded in the Record of Conflict of Interest Statement Acknowledgement. Please see 'Record of Conflict of Interest Statement Acknowledgement' [C:\Documents and Settings\ALD Penge\My Documents\ALD Life\Information Standard\C. Information Production System\Record of Conflict of Interest Statement Acknowledgement.xls].

The Fundraising and Business Development Manager is then responsible for working with them and overseeing all stages of the information production process. They have to consult with the Fundraising and Business Development Manager at each stage of production, and he/she will be responsible for going through the 'Information Production Checklist' with the third party information source. This is to ensure that we produce information in line with our Information Production Process as efficiently as possible.

The information product's draft version are internally monitored, go through various focus groups, be checked by our medical advisers, and require signing off by the CEO and Board of Trustees, as in line with our Information Production Process. Please see 'Information Production Process' [C:\Documents and Settings\ALD Penge\My Documents\ALD Life\Information Standard\C. Information Production System\Information Production Process.doc].

The Fundraising and Business Development Manager records all third party information sources we use in the production of information products including details about their skills, knowledge and expertise along with the initial requirement of the information product. Please see 'Third Party Information Source log' [C:\Documents and Settings\ALD Penge\My Documents\ALD Life\Information Standard\C. Information Production System\ Third Party Information Source log.doc].



He/she then evaluates third party information sources by assessing the information product against the initial requirements. Evaluations will be recorded in the 'Third Party Information Source log', which is then used to help us assess the suitability of the third party information source in the future.

C.15

We keep an electronic copy of each information product in its own file in our information product folder for as long as it is in production and for at least five years after it ceases to be available. All records in relations to the product such as draft and previous versions, research from medical sources, feedback from focus groups, our medical advisers or specific advisers are kept alongside the information product in its own file.

Each information product have a information production checklist form with dates of original publication, every subsequent review dates, references to sources including URLs, information provided by our medical advisers and specific profile of our target audience (if necessary).

These are maintained in the relevant file, and kept for as long as it's in production, and again for at least five years after ceasing to be available.

Any updated information will be recorded.

Backup copy of all files and folders relevant to our information products are kept on our network server as well as our dropbox server (both only accessible by those given sharing privileges). Back-ups are also made every six months on an external hard-drive. See 'Back-up Policy Statement' [C:\Documents and Settings\ALD Penge\My Documents\ALD Life\Information Standard\C. Information Production System\Back-up Policy Statement.doc].

Date adopted Jan 2013

Review Date Jan 2015

Signature  **Sara Hunt, ALD Life CEO**