

A Digital Curation Centre
'working level' guide



How To Write a Lay Summary

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in collaboration with the Patients Participate! project.



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How To Write a Lay Summary

Introduction

Lay summaries are short accounts of research that are targeted at a general audience. They play a significant role in most research grant applications and can also be useful in supporting wider public engagement with research. Lay summaries are particularly important for research in medicine and health, and are normally a prerequisite for grant applications made to the UK research councils and to medical charities. This guide will help you to understand what lay summaries are, how they are used and why they are important. It describes some general guidelines for writing lay summaries and explores some issues and challenges with lay summary provision. This guide should help researchers who are required to write lay summaries and organisations with an interest in public engagement with research, or those with responsibility for making research accessible. It also provides pointers to other resources to help with the writing of lay summaries. **Although the guide draws in particular from the experience of charities involved in communicating about research in medicine and health, the lessons and guidelines should be transferable to other disciplines.**

Why lay summaries are useful

Public engagement is a priority for funders of higher education. Funders expect universities to demonstrate the impact of research on the public, how they are meeting the needs of wider society, and the relevance and responsiveness of their research¹. As explained by the National Co-ordinating Centre for Public Engagement, evidence is growing that there are benefits to universities, to students and staff, and to society. Methods of public engagement include consulting, collaborating and informing, using different media such as presentations, podcasts and writing for non-specialist audiences. The benefits of public engagement are particularly recognised for medical and health research:

“If we want medical and health research to be of real benefit to patients and their families then we must strive to involve them more in setting the questions to which we are seeking answers, the way in which research is conducted and, finally, how it is disseminated and put into practice.

Time and again the evidence shows that service user involvement results in outcomes that are more relevant and useful.”

Simon Denegri (Chair of INVOLVE)²

INVOLVE, a national advisory group funded by the UK National Institute for Health Research, reports that involving service users helps at all stages of a research project, from developing the research question through to disseminating the results. The benefits of the direct involvement of service users in research have been identified as follows:³

- Increasing the relevance of the research
- Increasing recruitment to clinical research
- Improving the design of the research to address ethical concerns, improve the research tools and make it easier for the people taking part
- Improving the quality of the data and its interpretation
- Making it more likely that the findings of the research will be used to make a difference to service users' lives.

In medicine and health, there is some evidence that when researchers get closer to patients, significant conversations develop about the priorities for patients, which in turn may lead to new areas of research, for example patient-focused research related to living with the condition.⁴

Finally, involving the public in research could increase the likelihood of the research findings being used by others, as the public can have a stronger commitment to bringing about change.

“The service user who has been involved in research is often its most powerful advocate, promoting understanding among other service users and acting as ambassadors for the charity whether it be to the politician or the major donor.”

Simon Denegri (Chair of INVOLVE)⁵

Attracting the support and confidence of the public is also important to the organisations that fund research.

Lay Summaries are one form of writing intended to help communicate research to a non-specialist audience. They describe research in non-specialist

¹National Co-ordinating Centre for Public Engagement, *The case for public engagement*. Retrieved Mar 20 2012 from: <http://www.publicengagement.ac.uk/why-does-it-matter/case-for-engagement>

²Simon Denegri, cited in: TwoCan Associates, *User involvement in research: A route map*. Retrieved Mar 20 2012 from: <http://www.twocanassociates.co.uk/routemap/why-involve-service-users.php>

³TwoCan Associates, *User involvement in research: A route map*. Retrieved Mar 20 2012 from: <http://www.twocanassociates.co.uk/routemap/user-involvement-in-research-projects.php>

⁴Association of Medical Research Charities. (2009) *Natural Ground: Paths to patient and public involvement for medical research charities*. AMRC. Retrieved March 20, 2012 from: http://www.amrc.org.uk/our-members_natural-ground-patient-and-public-involvement-project_ppi-natural-ground

⁵Simon Denegri, cited in: TwoCan Associates, *User involvement in research: A route map*. Retrieved Mar 20 2012 from: <http://www.twocanassociates.co.uk/routemap/why-involve-service-users.php>

language and are meant for people who are not the immediate peers of the researcher. They can be required as part of grant conditions, either during the funding application process, or at the stage when research results are disseminated. Lay summaries are often written by researchers themselves, although some charities employ specialist writers for the purpose (see the CancerHelp UK case study on p. 7 for an example). Lay summaries are useful to the lay public but can also make research accessible to professionals in nearby fields. The next sections of this guide provide a definition of lay summaries, describe some ways in which lay summaries are used, present an overview of guidelines for writing lay summaries, and consider some challenges in lay summary writing.

Concepts

After reviewing the literature, Smith and Ashmore⁶ found that the most succinct definition for a lay summary was provided by INVOLVE's People in Research programme. This defines a lay summary in the following way:⁷

“A lay summary is a brief summary of a research project or a research proposal that has been written for members of the public, rather than researchers or professionals. It should be written in plain English, avoid the use of jargon and explain any technical terms that have to be included.”

How lay summaries are used

Lay summaries serve the general purpose of explaining research to the non-expert. There are different ways in which lay summaries can be used, both by members of the general public and by other researchers who are not specialists in the field of research.

Research grant applications often contain a lay summary or abstract which helps to explain *“why the research is being suggested, what researchers aim to achieve, and how this may impact on the rest of the research community”*.⁸ The AMRC Natural Ground report goes on to describe other ways in which lay summaries are used by some charities.

Patients or carers are being involved in research funding decisions.⁹ They have a direct interest in

the outcome of the research and experience of the disease, and they are also able to advise on the feasibility of the research. To participate fully in decision-making, patients and carers involved in funding committees need the lay summary to help them understand the research.

There are different models for how lay members input into funding decisions – they can be members of the funding panel, they can be part of a separate but parallel lay review process, or they can comment on the value of research projects and their feasibility. Some charities have patients sitting alongside the scientific members of the committee. Others have lay members who review applications in parallel to the scientific review. At the Alzheimer's Society applications have to be passed by lay members drawn from a consumer network before moving on to scientific peer review. The lay members give a score based on the importance of each application and how well it matches the research priorities of the society. They can also comment on each application.¹⁰

The Arthritis Research Campaign has a USER committee that looks at the practicality of doing research and questions the assumptions of researchers. They reported that, in one instance, *“our patient reviewer was the only person to spot that a researcher had assumed that people would only have one artificial joint – many people with arthritis have more than one replacement joint, and so the suggested blood test would provide unclear results”*.¹¹

As the AMRC Natural Ground report notes,¹² a common theme of involving patients in research activities is that patients have *“invaluable experience of living with the relevant condition and so are able to assess the feasibility of planned projects (even those that had been successfully peer reviewed) and provide a ‘reality check’*.” Even research that has been approved by research ethics committees can raise practical issues that make the project unacceptable to patients asked to participate. Lay summaries provide an accessible way for patients to understand what research is proposed so that they can input into the research process.

The Alzheimer's Society found that presentations at interview stage that had been simplified for the benefit of lay members resulted in presentations that were easier for the scientists on the panel to understand. Panel members are not always specialists in the particular field that the applicant is working in. This observation was also supported in the Patients Participate! discussions with academics, where one of our participants who sits on award panels reported that lay summaries were useful to her in her role as

⁶Mark Smith and Claire Ashmore. (2010) *The Lay Summary in medical research proposals – is it becoming more important?* Poster presentation at: *Making an Impact - Annual Conference of the Association of Research Managers and Administrators*, Manchester. Retrieved March 20, 2012 from: http://www.keele.ac.uk/media/keeleuniversity/ri/istm/documents/Lay_summary_poster_final.pdf

⁷People in Research, *Jargon buster*. Retrieved March 20, 2012 from: <http://www.peopleinresearch.org/about-this-site/jargon-buster/#laysumm>

⁸AMRC, *Natural Ground*, p. 11.

⁹AMRC, *Natural Ground*, p. 8.

¹⁰*Ibid*

¹¹AMRC, *Natural Ground*, p. 9.

¹²AMRC, *Natural Ground*, p. 10.

a reviewer. Smith and Ashmore suggest that the lay summary is a key part of the grant application, it being the only part of many applications that a busy reviewer may ever read.¹³

Lay summaries are used to describe clinical trials as part of recruiting participants. These descriptions help prospective participants to decide whether they want to be involved in clinical trials. Charities may also need to assess whether to tell service users about opportunities to take part in research. Asthma UK has developed policies and procedures, forms and guidance to help describe what would be expected from participants.

Some charities use lay involvement to develop their research strategies and to ensure that they fund research that is responsive to the needs of their members. Lay members help them to define research priority areas. The charities also need to communicate research progress effectively. The Muscular Dystrophy Campaign provides an example of a charity with an aim of making complex research more accessible and understandable. It has involved a focus group “Talk Research” in the work of its research communications staff, providing easy-to-understand versions of complex research advancements, through a weekly news service on the website and a yearly research magazine. The involvement of “Talk Research” was reported as being a “great success” and “has led to a new way of communicating research and increasing website visits”.¹⁴ Lay summaries are one of the tools that help to achieve these aims.

Guidelines for writing lay summaries

Some charities and other organisations provide guidelines for researchers with advice on how to write a lay summary, or more general advice on presenting information in an accessible way. In August 2011, UKOLN reviewed a selection of guidelines, collected by the project partners the AMRC and the British Library during discussions held with stakeholders in the Patients Participate! project (see box on p.5), alongside other advice for writing lay summaries.

The guidance in those documents has been synthesised and is presented below. These guidelines can be turned into questions to ask about a lay summary, to check if the summary meets the criteria e.g. Is the summary appropriate for the readership? Other sources of help available include example lists for some of the guidelines, such as lists of plain English words, guidelines provided by charities, and information and resources made available by organisations with a remit to promote public engagement. These sources are listed in the further information section at the end of this guide. Some of

the guides produced by charities are available online, but others were intended for internal use by the charity. Co-ordination would be required so that these guides are made more widely available and shared for more general use.

Characteristics of a summary document (lay summary)

Appropriateness for readership

The author should be aware of (and indicate) the intended audience for the text.

For example, potential participants in studies OR the general public.

Grammar, punctuation and spelling

Grammar and punctuation should be accurate, and spelling should follow appropriate conventions. *For example, UK spelling should be used if the text is to be published to a UK audience.*

Level of difficulty of text (words and structure)

The text should be written in an easily readable style. The author should use short, clear sentences broken up into paragraphs for readability, and avoid complex grammatical structures where possible. The author should use everyday English words in place of complex words.

Structure

The text should be ordered logically and flow naturally. *For example, ideas should be introduced as they are required, and new ideas usually should not be introduced late in the text.*

Avoid complex or meaningless terms and phrases

Many terms used in academic English are either overcomplicated or contain no useful information. *Examples include terms such as ‘virtually’ or ‘literally’ or archaic language (e.g. amidst, whilst), as well as verb choices such as ‘purchase’ used in place of the simpler ‘buy’.*

Expressing ideas in the active voice

Text should be written in the active voice (“I... you..”) and second person (“you”) should be used in place of third person (“he/she”). *For example: “You will have chemotherapy” rather than “Chemotherapy will be given to you”.*

Positive phrasing

Sentences should be phrased positively, rather than negatively. *For example, “You will have repeat appointments at least once a fortnight”, rather than “The usual practice is not to schedule repeat appointments more frequently than once a fortnight”.*

¹³Smith and Ashmore, *The Lay Summary in medical research proposals*.

¹⁴AMRC, *Natural Ground*, p. 31

Adhering to convention

The text should have the correct word count and the author should structure it according to relevant guidelines (such as funders' guidelines).

Straightforward to read

The writer should limit the memory load on readers – don't ask them to remember too much jargon/abstract information.

Clear theme

A good and relevant title should be provided, and the first sentence should offer a concise introduction to the text.

Content

The text should provide answers to the essential questions: Who, What, Where, When, Why, How? *For example, the reader should easily be able to find answers to questions such as 'By whom was the research funded, and why?'*

Relevance, application and benefits

Aims and objectives should be clearly signalled. *For example, the 'point' – the impact – of the work should be clearly understood.*

Everyday examples

Give concrete everyday examples wherever possible.

Timescales

Timescales, if relevant, should be clearly defined.

Risks

If it is relevant to the activity you are summarising, make sure that any risks attached to the activity are clearly identified and described.

Person-centred language

The language used should be person-centred, rather than focusing on circumstance, illness or disability. *For example: 'people with a disability/illness' is preferable to 'the disabled/invalids'; a person 'has cerebral palsy' rather than 'is a victim of cerebral palsy'.*

Appropriate tone

The text should not be written to entertain.

Lay Summary guidelines reviewed by Patients Participate!

- Tips for Writing a Lay Summary (University of Manchester, Faculty of Engineering and Physical Sciences)
- The Lay Summary in medical research proposals – is it becoming more important? (Smith and Ashmore, 2010)
- Asthma UK Foundation grant round: Guidance Notes for lay reviewers. (Asthma UK)
- Writing a lay abstract (Asthma UK)
- Frequently Asked Questions (FAQs) about Asthma UK's annual grant round. (Asthma UK)
- Trials database preforms (CancerHelp UK)
- Editorial policy (CancerHelp UK)
- Trials database editorial policy (CancerHelp UK)
- Writers' guidelines (CancerHelp UK)
- A brief guide to writing for a lay audience. (Cancer Research UK)
- General guidelines for the Muscular Dystrophy Campaign website (Muscular Dystrophy Campaign)
- How to write a clinical trial summary (Muscular Dystrophy Campaign)
- Muscular Dystrophy Campaign Lay Grant Application Form – guidance Notes (Muscular Dystrophy Campaign).
- Project Grant Plain English Summary (The Stroke Association)

Roles and responsibilities

Institutions are increasingly being encouraged to fulfil public engagement responsibilities. The Research Councils UK *Concordat for Engaging the Public with Research* offers the principle¹⁵ that research organisations need to have a strategic commitment to public engagement. Institutions have a role in encouraging researchers to communicate with the public and to make their research accessible. They may be able to provide training to researchers and those in training, e.g. post-graduates, through courses and events. They can raise awareness of and offer resources on writing lay summaries.

Funders (including public funding bodies and charities) may require the production of a lay summary as part of their grant conditions. Funders should provide clear guidance on the aims of the lay summary and describe how it will be used. They must explain to researchers why this additional information is needed, and stress the importance of doing it well.¹⁶ They may need to design structures and templates to assist with the production of lay summaries. They may need to ask researchers for further information or provide training on writing better lay summaries.

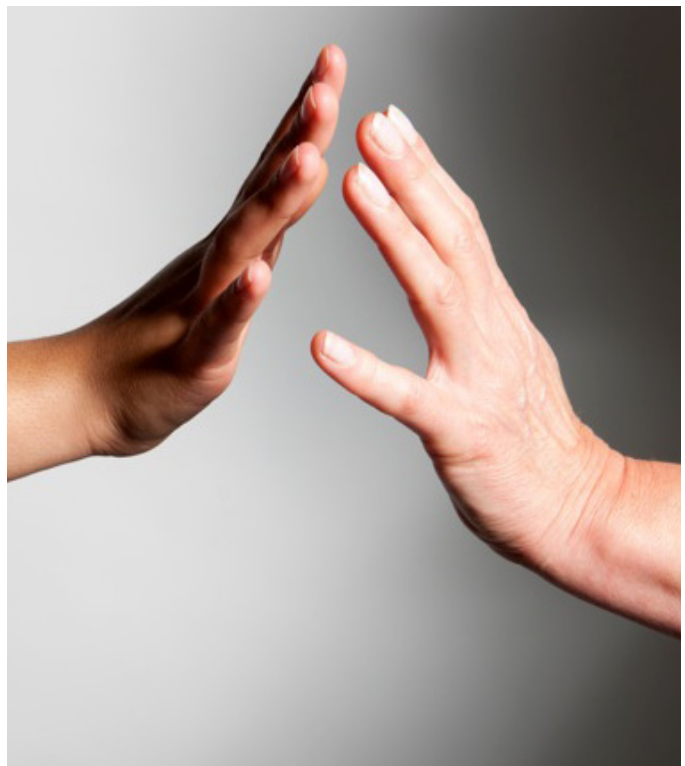
If scientific and lay members are commenting on different aspects of an application during review, the funding body must ensure that this is clear to all panel members. The chair of the panel should be briefed on how to manage any confusion.¹⁷

Researchers have a duty to make their research accessible to a wide audience. They may need to provide lay summaries to fulfil grant conditions or as part of an application for funding. Researchers need to perceive the writing of lay summaries as part of their wider remit to communicate with the public. They must seek to acquire the skills needed, and incorporate the teaching of those skills to junior members of their teams. Some researchers actively utilise lay summaries as an effective method to engage the public.

Service providers have a responsibility for the dissemination of research findings, including dissemination to the general public. Research is accessed in different ways and through different portals. There is a role for publishers of research and the funders of research to consider how the research can be presented using different forms, formats and channels to communicate it most effectively to different audiences. Different levels of detail and routes for navigating the information should be investigated and tested.

In the Natural Ground report, the AMRC provides the following key learning points for organisations that wish to promote and support the writing of lay summaries:¹⁸

- The method used to develop plain English versions of research will depend on the organisation, its resources and the perceived need for the information.
- Information provided to lay members should be relevant to their needs and the task they are being asked to do.
- Different groups of lay people require information in different formats or even different information – it is vital that participants are involved in the process of deciding what information is relevant to them and how it should be presented.
- Researchers need to be assured that providing a truly lay abstract will not mean their application is marked down by scientific peer reviewers as being unscientific.
- Providing more lay-friendly information was a culture-change for researchers. They require guidance on what information should be provided and clarity on what will happen if they do not comply.



¹⁵Research Councils UK, *Concordat for Engaging the Public with Research*. Retrieved Mar 20 2012 from: <http://www.rcuk.ac.uk/per/Pages/Concordat.aspx>

¹⁶AMRC, *Natural Ground*, p. 9.

¹⁷*Ibid*

¹⁸AMRC, *Natural Ground*, p. 11.

Examples

The Patients Participate! Case Study Report¹⁹ described some narratives gathered to answer the question: Who is currently producing easy-to-understand information relating to biomedical research for the public and how do they do it? The examples in the case studies are illustrative of some of the methods organisations currently employ and some of the challenges in doing it well. They describe useful methodologies and approaches for others who are starting out, those trying to increase the volume or improve the quality of their lay communications, or seeking to include patients in their activities in meaningful ways. Two of the examples are presented here.

From: Patients Participate! Case Study Report (2011).
<http://blogs.ukoln.ac.uk/patientsparticipate/files/2011/10/Case-study-report-Final.pdf>

CancerHelp UK

Cancer Research UK is a large charity with over three thousand staff and a research budget of £300 million. CancerHelp UK is their flagship information website, forming part of a communication strategy which employs new media such as Twitter and Facebook. As part of their commitment to providing easy-to-understand information about cancer and cancer care, for the past eleven years CancerHelp UK has employed a team to provide plain English summaries of ongoing clinical trials.

On the site they aim to list all cancer trials and studies recruiting UK participants – these trials and the volunteers that take part in them are vital to developing new treatments and methods of cancer detection. Having clear, easy-to-understand information about a trial is crucial for patients considering participating in it. The writing team has years of clinical knowledge and experience, and this is considered critical in being able to translate technical information relating to the trials in a way that patients will find useful. Having dealt with patients' questions in a clinical setting the team also understands the types of practical issues that will concern patients.

CancerHelp UK produces a plain English summary for each individual trial, which includes information from the trial protocol and the patient information sheet. The patient information sheet is intended to provide all the necessary information relevant to patients and the public so they can make an informed decision about participating in a trial.

The team have developed their own guidelines, editorial policies and style guides (all available on their website), founded on patient feedback from evaluation and review of the information. To ensure quality of their summaries, the CancerHelp UK team has a rigorous internal editorial process to ensure that the information provided will answer the patients' questions, is pitched at the appropriate level and avoids jargon of any kind. The trial team is asked for final approval on the summary, a process that is often iterative and it can take some time to come to a consensus on summary content, style and language.

<http://cancerhelp.cancerresearchuk.org/utilities/about-cancerhelp-uk/cancerhelp-uk-policies/>
<http://cancerhelp.cancerresearchuk.org/trials/>

PLoS Medicine

PLoS Medicine is a peer-reviewed, international, open-access, web-based journal containing original research and analysis relevant to human health. The journal is published by the Public Library of Science (PLoS), which was founded by scientists in order to provide unrestricted access to scientific research outputs. PLoS journals also have as one of their core principles:

'developing tools and materials to engage the interest and imagination of the public and helping non-scientists to understand and enjoy scientific discoveries and the scientific process'.

To this end some PLoS journals provide lay summaries alongside research articles. PLoS Medicine includes one of these summaries embedded within every research article they publish. Following article submission, summaries are written by the journal's editors and are pitched at a level that the general public with no medical or biomedical background can understand. The aim of these summaries is to try to make all published articles accessible to anyone who wants to try to understand them, which is central to the PLoS ethos. A set of internal style guides helps to ensure consistency in structure and language. These guides consist of broad headings (background, rationale for undertaking the research, research findings and the importance of the results in a wider context) and a list of Dos and Don'ts. Editors also include links to further information that might be useful to the reader. The summary and links are included in the copy-edited version of the article, often with a set of questions for clarification which is then sent back to authors for sign-off. This gives researchers the opportunity to fact-check summaries, comment on the information, and add links to other websites and resources.

PLoS Medicine is a highly selective journal, publishing a small number of research articles, allowing their editors to feasibly write a summary for every article. Writing them takes time and skill.

<http://www.plosmedicine.org/>

Training and support examples

Some universities offer services to researchers and students to help them acquire lay summary writing skills. This help can take the form of courses or training activities, written guidance, and review and discussion.

The University of Manchester runs a training programme for graduates through its eProg Development Programme. Half day interactive workshops are held with small group discussions in which examples of lay summaries are deconstructed including samples of the participants' draft summaries, with feedback provided. The Faculty of Engineering and Physical Sciences also publishes two resources for Graduates and Researchers: a tip sheet and a summary of guidance from research funders.

The University of Illinois offers a web page describing lay summaries and their different uses. Their Research Development Services offer a review service for research summaries.

The University of Bath hosted a conference entitled Developing Writing in STEM disciplines in September 2011, as part of a South West HE project on developing writing skills, to identify good practice in developing writing skills, attitudes, identities and values.

Current issues and challenges

The production and use of lay summaries is an evolving practice, and cultural and practical challenges remain, both in producing well-written lay summaries that are accessible to the intended audience and in providing services that reach the public and are useful.

Writing lay summaries is inherently difficult or not enjoyable.

Most researchers find writing a lay summary a difficult task²⁰ which may require different skills to other writing tasks that they perform. In the Natural Ground report, the AMRC reported that “*researchers often continued to provide summaries that were impenetrable to patients and the public*”; the information provided was insufficiently clear, despite requests to simplify it.²¹ CancerHelp UK found that clinical researchers often did not have the necessary skills, and they now employ a team of people with the defined skills and training for writing for a lay audience.

Some researchers enjoy writing for the public and embrace the value of helping the public understand

science,²² others consider writing their research in accessible language to be a time-consuming challenge. Moreover, writing lay summaries has to fit alongside other demands and workloads, often juggled with deadlines for grant submissions, when other parts of the grant are considered more important. The lay summary can become a chore, and feel like a difficult and pointless exercise, particularly if researchers do not feel that they are equipped with the required skills.

Researchers may need to be persuaded of the benefits.

For researchers to commit the time and effort to learn the skills and write good summaries, they need to believe that public engagement is one possible approach to improving the quality, relevance and impact of their work. Not everyone will buy in to this argument, and the anticipated benefits and processes may need to be spelled out. Until researchers see the benefits for themselves, writing lay summaries can be perceived as a burden. Positive examples from other fields may be a useful tool to demonstrate benefits.

Defining the audience.

One of the key pieces of advice given to lay summary writers is for the summary to be compelling and understandable by the audience it is written for. However the audience is often either poorly defined or described in ways that may not be helpful to the writer. Smith and Ashmore²³ illustrate with examples that guidance from funders can be contradictory or unclear.

Read-aloud and review by non-specialists as methods of checking lay summaries.

Two methods are commonly suggested to lay summary writers to check the appropriateness of lay summaries. These are to read the text aloud to yourself, and to ask someone else who is not the domain expert, and preferably from the intended audience, to read and comment on it. There are reports in the literature that reading aloud helps to detect errors, although there is a lack of information on the specific task of using this method for lay summary checking. Studies do suggest that finding errors in texts written by others is easier than finding errors in one's own text. However some questions remain about the specific skills needed and how they can be taught. Error detection through reading is quite complex and does depend on who is doing the reading. Further research into both these methods for checking lay summaries would be useful, for example to suggest some effective guidelines for proof-reading of lay summaries.

Providing support for lay summary writing (templates/forms)

The lay summary may need to be presented in a style and structure that is different to that normally used in applications for funding or when writing for journals

¹⁹Patients Participate! Case studies (2011). Retrieved Mar 20 2012 from: <http://blogs.ukoln.ac.uk/patientsparticipate/files/2011/10/Case-study-report-Final.pdf>

²⁰Smith and Ashmore, *The Lay Summary in medical research proposals*.

²¹AMRC, *Natural Ground*, p.11

²²Stephen Curry. (2008) *Run that by me again? On the joys of the lay summary*. LabLit.com. Retrieved March 20, 2012 from: <http://www.lablit.com/article/435>.

²³Smith and Ashmore, *The Lay Summary in medical research proposals*.

and conferences. The Stroke Association reported that survivors and carers would require different information from that in the traditional application form.²⁴ The lay summary must answer the questions that lay people have about the research. For example patients trying to decide whether to join a clinical trial may want information about the number of hospital visits required from participants. Templates and forms with directed questions can help to make sure that the questions of interest to the lay reader are answered. One example is provided by The Stroke Association, where the questions that guide the lay summary writing focus on the involvement of stroke survivors.

Conflicting guidelines and requirements.

One issue with forms for submission of lay summaries is that sometimes conflicting guidelines may be encountered. For example the requirement to write in paragraphs is in tension with the need to fit text within the confined space of a form. Similarly, adding medical terms alongside plain English words for conditions will use up words within a tight word limit count. There is also variation in the word count that is considered suitable for a lay summary. Smith²⁵ found that Research Councils UK allow up to 4000 characters, but the limits set by charities can vary between 100 to 1000 words.

More research is needed into what makes a good lay summary.

Although guidelines are being developed and some commonality can be identified between the guidelines, it is not clear if the practice and advice is grounded in evidence. Next to no research is available on what makes a good summary and there is a scarcity of evidence of lay summaries and guidelines being tested for effectiveness. Smith and Ashmore²⁶ note that funders differ in what they expect and there seems to be no consensus in how to write a lay summary.

Services, models of access and use of lay summaries.

Curry²⁷ explains his doubts as to whether the public ever access lay summaries. PLoS Medicine reports that there is a low level of interaction by the public using tools for rating, notes, links and threaded discussions provided on their site, and they do not yet have a good understanding for the lack of interaction.²⁸ If lay summaries are going to be a means of bringing research to the public, helping to foster relationships between researchers, those that fund the research and those that are impacted by the research, they need to be easy to find, easy to access, easy to navigate, and easy to interact with. This may require different service models, delivery formats and collaboration and co-ordination between different organisations that are part of the research process. Some charities, such as CancerHelp UK, carry out their own evaluation on what makes for an effective website for the public. The

challenge is now for the research community to start recording lessons learnt and find ways to share them.

Gathering evidence of impact.

Organisations may need to justify allocating resource and effort to the writing of lay summaries. Organisations and individuals need to collect information about the impact of their lay summaries as examples of good practice and to be able to demonstrate effectiveness. They may also be able to share examples with the wider community. Individuals may be able to use the impact of lay summaries as evidence for the benefits of their research, to justify further funding into the research area. Furthermore, evidence of the use of lay summaries for the intended purposes would help make the case to researchers.

Further information and bibliography

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CancerHelp UK. *Writer's guidelines*. Retrieved March 20, 2012, from: <http://cancerhelp.cancerresearchuk.org/utilities/about-cancerhelp-uk/cancerhelp-uk-policies/editorial-policy/writers-guidelines>

²⁴AMRC, *Natural Ground*, p. 31.

²⁵Smith, M. (2009) *The Lay Summary in Medical Research - Why and Wherefore*. *Midlands Medicine* vol.25, no.5, pp.191-195.

²⁶Smith and Ashmore, *The Lay Summary in medical research proposals*.

²⁷Curry, *Run that by me again?*

²⁸*Patients Participate! Case Studies*.

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