Communicating health research to a diverse audience: what can plain language summaries offer?

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A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy.

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Statement of originality

This is to certify that to the best of my knowledge, the content of this thesis is my own work. This thesis has not been submitted for any degree or other purposes.

I certify that the intellectual content of this thesis is the product of my own work and that all assistance received in preparing this thesis and sources have been acknowledged.

Name: Karen Gainey Date: 23rd June 2025

Abstract

Plain language summaries (PLSs) are research summaries written with a non-expert audience in mind. PLSs have been a part of academic publishing for several decades and serve as a means of providing accessible research to a diverse audience. Mainly located in journal articles in text-only format, PLSs also form part of research funding applications for consumer groups or government agencies and can be found in audio, visual and graphical formats. Although growing in popularity in recent years with journal publishers and researchers, most health and medical journals still do not publish PLSs. Of those that do, they are not a mandatory requirement. PLSs play a valuable role in communicating health research to a diverse audience, however they remain an underutilised resource.

Aims

This thesis focuses on aspects related to the implementation, dissemination and use of PLSs in health and medical journals and aims to: 1) provide an understanding of the author instructions for writing PLSs from health and medical journals (Chapter 2); assess the level of compliance of published PLSs to their author instructions in health and medical journals (Chapter 3); obtain an understanding of what is most important to people living with chronic medical conditions who read PLSs (Chapter 4); and gain knowledge about the perspectives of editors of health and medical journals on the production, publication and dissemination of PLSs (Chapter 5).

Methods

The first study of this thesis (Chapter 2) is a scoping review of the author instructions available in health and medical journals for writing PLSs. In this scoping review, I screened 534 journals that covered 11 journal categories linked to the top 10 non-communicable diseases. For the journals found to publish PLSs, author instructions were analysed in detail, including deductive coding of specific 'elements' (e.g. word count/PLS length, structure, purpose, content, guidance on the use of plain language) and 'characteristics' (e.g. label used for the PLS, whether the PLS was mandatory or optional). This study was followed up with a three-part systematic environmental scan (Chapter 3), which assessed the degree of adherence of PLSs in the journals from the scoping review (Chapter 2) to the PLS author instructions for each journal. Also, I conducted a health literacy assessment of all PLSs, measuring the grade reading level and percentage of complex language using the SHeLL Editor. I next conducted two qualitative studies (Chapters 4 and 5), using semi-structured interviews and applying the principles of reflexive thematic analysis to both. First, I surveyed 19 people with chronic medical conditions from across six countries who read and use PLSs to find out what is most important to them with PLSs in terms of the content, layout, length, design and the labels used (Chapter 4). Second, I planned a final qualitative study (Chapter 5) involving 20 journal editors to understand better the publication process and any barriers or facilitators in developing, publishing and disseminating PLSs. Editors represented 23 journals across eight publishing groups and six countries, including Australia.

Results

From the initial 534 journals screened in the scoping review (Chapter 2), only 27 (5.1%) published PLSs. Most (70%) did not require a PLS. There was wide variance in the author instructions between journals, with varying levels of detail. For example, word count or length ranged from 100 to 850 words. Although most (70%) of journals included guidance to avoid jargon, acronyms and abbreviations, only one suggested using a readability tool. Co-design was overlooked, with only one journal suggesting consumer involvement. In the environmental scan, I searched 26 journals and found 20 (76.9%) of these published PLSs. When assessing compliance to PLS author instructions, no journal's PLSs achieved 100% compliance. However, two journals achieved a high rating (≥85% compliance). Five journals (20%) achieved low (≤ 50%) or very low (≤ 35%) compliance. The health literacy assessment showed that the mean grade reading level for all PLSs was grade 15.8 (range 10.2–21.2), and the mean percentage of complex words was 31% (range 8.5%–49.8%).

In the first qualitative study (Chapter 4), through the process of reflexive thematic analysis, four themes were developed: (i) 'Accessing information in a competitive landscape of health information'; (ii) 'I really don't see the patient in this at all'; (iii) 'Co-design should be meaningful, not tokenistic'; and (iv) 'A way forward: Approach PLSs with creativity'. Most

participants were female, aged 60–69, had a university-level education, resided in Australia, and had read a PLS the month before the study. Participants highlighted the importance of respectfully providing PLS readers with actionable information, using an appropriate level of jargon and a variety of formats to accommodate the diverse needs of readers. In the second qualitative study (Chapter 5), I developed five themes: (1) When good intentions clash with practical realities; (2) Whose job is it anyway?; (3) A cautiously optimistic approach to support from artificial intelligence (AI); (4) Blind spots and broken loops; (5) A 'One size fits all' approach doesn't work. Most participants were male, resided in the United Kingdom or Australia, had worked as an editor for at least five years, and reported making up to 10 editorial decisions weekly. Editors were most commonly affiliated with Taylor and Francis and Wiley publishing groups. The editors' experiences varied in terms of the support and autonomy from their publishing companies, noting challenges associated with a lack of data about PLS readership. Opinions were mixed on the integration of alternate formats and the use of AI to produce PLSs. However, all agreed that for the latter, human intervention to check the output of AI was essential.

Discussion

The findings from this thesis highlight the challenges that exist in the field of PLSs. Despite some advancements to help make PLSs more accessible and available, much work must be done to better cater for the diverse audience of PLSs. Journal author instructions for PLSs vary substantially between journals, and researchers' compliance with these instructions is moderate at best. Complicating matters is due to a lack of governance systems from many journal publishers to manage better quality control and a lack of consensus from editors and publishers about prioritising PLSs for their journals. Support (e.g. clear instructions and advice) for researchers to write PLSs that conform to journal guidelines and health literacy principles is also lacking. Findings from this thesis suggest that PLSs produced with end-user input could elicit PLSs that better meet audience needs, focusing on information that is actionable, accessible and written with helpful content that is detailed but still respectful of the reader. Although adopted by some publishers, most do not have systems to promote PLS co-design with end users.

Conclusion

This thesis demonstrates where gaps exist in the collective understanding of how PLSs could be optimised to communicate health research to the public. Such gaps exist in evaluating and challenging assumptions related to current practices in producing, publishing and disseminating PLSs. Most of the work in the field of PLSs has been experimental in design, with less attention given to the adoption, implementation and sustainability of PLSs. Focus on these areas is vital as PLS application into practice remains inconsistent. PLS have the power to meaningfully engage people with trustworthy research, playing an essential role in the oftentimes confusing landscape of health information. Attention must be given by scholarly publishing and academia to support researchers to write and distribute PLSs, providing access to a diverse audience of people.

List of publications included

The publications that comprise this thesis are:

1. Gainey, K.M., Smith, J., McCaffery, K,J., Clifford ,S., & Muscat, D.M.M. (2023). What Author Instructions Do Health Journals Provide for Writing Plain Language Summaries? A Scoping Review. *The Patient – Patient-Centred Outcomes Research*, 16, 31- 42. Available from: https://doi.org/10.1007/s40271-022-00606-7.

2. Gainey, K.M., Smith, J., McCaffery, K., Clifford, S & Muscat, D. (2024). Are plain language summaries published in health journals written according to instructions and health literacy principles? An environmental scan. *BMJ Open*, 14:e086464. Available from: https://doi.org/10.1136/bmjopen-2024-086464

3. Gainey, K.M., McCaffery, K & Muscat, D. (2025). Perspectives of people with chronic illness about plain language summaries: a qualitative analysis. *Health Promotion International*, 40(2), daaf044. Available from: https://academic.oup.com/heapro/article/40/2/daaf044/8116443

4. Gainey, K.M., McCaffery, K & Muscat, D. (2025). What do journal editors think about opportunities and barriers in the advancement in the publication of plain language summaries? A qualitative analysis. Under review.

Authorship attribution statement

I, Karen Gainey, conducted the research presented within this thesis during my PhD candidature from 2018 to 2025 in the Sydney School of Public Health, Faculty of Medicine and Health, at the University of Sydney, Australia.

I conducted this research under my primary supervisor, Associate Professor Danielle Muscat (DM) and my auxiliary supervisor, Professor Kirsten McCaffery (KMc). Other contributors to this work include my colleagues within the Sydney School of Public Health Dr Jenna Smith (JS), Professor Steven Kamper (SK) and Associate Professor Adrian Traeger (AT), and Sharon Clifford (SC) who acted as a consumer representative. This work was supported by a University of Sydney Postgraduate Research Training Program fee offset. No content produced by generative AI tools has been used in the preparation of this thesis.

I am the first author on the four manuscripts (three published and one under review) that comprise this thesis. I made a substantial contribution to each manuscript and was responsible for study design and methods, obtaining ethics approval, recruitment and data collection, research data management, analysis, drafting manuscripts and revisions following peer review. The specific contributions made by me and all co-authors for each chapter are listed below:

Chapter 1: Introduction

KG wrote the chapter with critical feedback from supervisors (DM and KMc).

Chapter 2: What author instructions do health journals provide for writing plain language summaries? A scoping review.

KG, SK, AT, DM and KMc were involved in the conceptualisation and design of the study. KG coordinated the study. KG and JS performed data collection and analysis. KG drafted the manuscript with critical feedback from all authors. KG and SC co-wrote the plain language summary for the manuscript.

Chapter 3: Are plain language summaries in health journals written according to instructions and health literacy principles? An environmental scan.

KG, DM and KMc were involved in the conceptualisation and design of the study. KG coordinated the study. KG and JS performed data collection and analysis. KG drafted the manuscript with critical feedback from all authors. KG and SC co-wrote the plain language summary for the manuscript.

Chapter 4: Perspectives of people with chronic illness about plain language summaries: A qualitative analysis.

KG, DM and KMc were involved in the conceptualisation and design of the study. KG coordinated the study. KG conducted data collection. KG and DM were involved in data analysis. KG drafted the manuscript with critical feedback from all authors. KG wrote the plain language summary for the manuscript.

Chapter 5: What do editors of medical journals think about opportunities and barriers for advancement in the publication of plain language summaries? A qualitative analysis.

KG, DM and KMc were involved in the conceptualisation and design of the study. KG coordinated the study. KG conducted data collection. KG and DM were involved in data analysis. KG drafted the manuscript with critical feedback from all authors. KG wrote the plain language summary for the manuscript.

Chapter 6: Discussion

KG wrote the chapter with critical feedback from DM and KMc.

Student name: Karen Gainey Date: 23rd June 2025

As primary supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statements above are correct.

Supervisor name: Danielle Muscat Date: 23rd June 2025

Ethics approval

Ethics approval was obtained by the University of Sydney Human Research Ethics Committee for the qualitative studies (Chapters 4 and 5), protocol numbers 2019/1003 and 2024/HE001170 respectively. In both studies, all participants provided their informed consent prior to participation. Ethics approval was not required for the studies in Chapters 2 and 3. Chapter 2 involved a scoping review of publicly available information, and did not include human participants, personal data, or identifiable information. The data used in Chapter 3 was generated from the results of Chapter 2.

Ethics approval letters for Chapters 4 and 5 are provided in Appendix C (i) and Appendix D (i) respectively.

Acknowledgements

Since I began my PhD in late 2018, I have felt a range of emotions. At times, I have felt overwhelmed by the unique opportunity available to me, frustrated by the knockbacks from journal editors as I sought to get my first paper published, excited to be accepted to speak at my first international conference and grief-stricken by personal loss. Throughout this entire time, I have had the unconditional support of many people, and without them, I would not have been able to make it to the end of this fantastic journey.

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To my late mother, Ruby, the past year without you has been one of the hardest of my life. Even though your diagnosis meant that you didn't understand what I was studying, you gave me your unconditional support, nonetheless. When I think back to the many times you would ask me how my PhD was going, the conversations would go something like this. "How's Uni going?" "Good, I've just finished doing X". "Oh, so it's all finished now?" "No, Mum, I still have 18 months to go" "Oh well, keep going. You'll get there". I did get there, and I know you would be proud of me if you were here now.

To my supervisors, Associate Professor Danielle Muscat and Professor Kirsten McCaffery, there are too few words to express your impact on my PhD experience adequately. I knew I was in safe hands from the moment I met you both. Through the ups, downs and in-between moments, I'm grateful that you allowed me to flourish in my unique way. We have laughed, we have cried, and although we haven't always agreed, we have respected each other. I have had the time of my life and can't imagine doing my PhD with anyone else.

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To the team of healthcare professionals who have diagnosed and treated me, you have helped hold me together physically. To the mental health care professionals, you have literally helped keep me sane during this stressful time.

Finally, to the books on the shelves left unread, guitar sitting idle, people not visited, tennis balls not hit, and canvases left blank, I’m on my way.

Table of Contents

Glossary of terms

I have provided this glossary of terms because this thesis contains terms that are novel or have multiple or contextually dependant definitions. The full references cited below are included in the reference list for Chapter 1 of this thesis.

Author instructions/author guidelines

Throughout this thesis, these terms are used interchangeably. Author instructions or author guidelines refer to the specific details provided by journals to guide authors on how to write a plain language summary. They are usually located within the submission instructions or guidelines on the journal website.

Complex language

Based on reports from the Health Literacy Editor, complex language refers to the proportion (percentage) of words that are uncommon in English, acronyms, or words with a suggested alternative in the tool's thesaurus (Mac et al., 2022).

Consumer, patient and public

There is no universally agreed-upon term for members of the community who have a special interest in health research, either through strong health information-seeking behaviours or through involvement in the research process. I use the terms consumer, patient and public synonymously throughout this thesis.

Health literacy

A useful model of health literacy outlines four dimensions across three health domains. It covers the ability of someone to access/obtain, understand, process/appraise and apply/use information related to health care, disease prevention and health promotion (Sorensen et al., 2012).

Informed patient

This term describes those motivated to seek health information through sources such as the Internet rather than relying on that supplied by their treating medical practitioner (Kivits, 2004).

Plain language summary (PLS)

Condensed summaries of research articles written in plain, easy-to-understand language aimed at a non-scientific audience (Wada et al., 2021).

Plain language summary of publication (PLSP)

A type of enhanced format that serves a similar function to that of PLSs; however, notable differences make them more discoverable and freely accessible as they are not housed behind paywalls. As a separate article category with their own DOI number, PLSPs can be indexed by catalogues such as PubMed, Medline and Google Scholar (Rosenberg et al., 2023).

Readability

Readability is an objective way of assessing the suitability of written information for a non-expert audience. Readability formulas such as the Simple Measure of Gobbledygook (SMOG) Index, the Flesch Kincaid Grade Level (FKGL), and the Automated Readability Index (ARI) do this by estimating a text's equivalent school-grade reading level (Mac et al., 2022).

Chapter 1. Introduction

Background

Value of plain language summaries in the landscape of health information

Consumers and patients with specific health conditions rely on high-quality information to make informed decisions about their health and care. In today's modern digital environment, many seek health information beyond that provided by their treating medical practitioner, turning to traditional and social media, internet search engines, consumer health organisations, peer-to-peer networks and academic research (Pushparajah et al., 2018). Today, the challenge is not a lack of health information; it is working out what health information is reliable and what is not from the overabundant supply (Song et al., 2024; Soroya et al., 2021). Although the Internet is a popular source of health information, its unregulated nature poses a threat (Zhang et al., 2015). The sharing of low-quality health information or health information before it is fact-checked can lead to the spread of misinformation and disinformation known to erode public trust in science and evidence-based health care (Zhang et al., 2015). The impact of misinformation was highlighted by the COVID-19 pandemic, which showed what can happen when unreliable health messages are spread at the local community, national and global levels (Cooks et al., 2022; Islam et al., 2020; Kouzy et al., 2020). Paakkari et al (2021) also highlight the often overlooked issue of missed information. Health information can be missed altogether when access is limited, often due to factors such as low health literacy, medical conditions that affect cognition or mental health, and/or lower levels of education. (Paakkari et al., 2021).

One way of combating misinformation is to provide the public with peer-reviewed health research in a form that is accessible and easy to understand without the need for expert or technical knowledge. Health research is one of the most reliable types of health information; however, it is not always accessible or written with the public in mind (Wen & Yi, 2023). Plain language summaries (PLSs[1]) seek to overcome these existing barriers. PLSs

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[1] Throughout this thesis and the studies contained within it, I will use the acronym PLS to refer to the singular form and PLSs to refer to the plural form of the term ‘plain language summary’.

are condensed summaries of research articles written in plain, easy-to-understand language aimed at a non-scientific audience (Wada et al., 2020). PLSs may benefit many stakeholders, including consumers/patients, caregivers, agencies that fund health and medical research (government or private, not for profit), non-specialist researchers, health care practitioners, consumer groups, policymakers and media representatives. Regardless of the audience, the primary function of PLSs is to take technical, scientific health research and communicate it to the reader in a way they can easily understand and use. PLSs may be referred to by several labels or terms. In addition to 'Plain language summary', popular labels include, but are not limited to, 'Lay summary', 'Plain English summary' and 'Author summary' and 'Patient summary' (FitzGibbon et al., 2020).

Most commonly, PLSs are text-based; however, many journals offer alternative formats incorporating audio and visual elements, e.g., infographics (Rosenberg et al., 2023). Studies have shown mixed results regarding preferences and perceived value and effectiveness of each format in conveying research findings (Bredbenner & Simon, 2019; Buljan et al., 2018; Pferschy-Wenzig et al., 2016). In the context of this thesis and the studies within it, I refer specifically to text-based PLSs written by an author of the accompanying research article unless otherwise noted. This decision was based in part on the dominance of text-based PLSs in health and medical journals (Gunn, 2024), with the intention that focusing on a single format will contribute to transferrable learnings for other formats that are still emerging.

Plain language summaries have been reported to make research more accessible and understandable and increase knowledge compared to other health communication formats (Riganti & McKinnon, 2023). A 2022 systematic review of theory, guidelines and empirical research related to PLSs identified several studies which assessed objective knowledge gain resulting from PLSs (e.g., Alderice et al., 2016; Anzinger et al., 2020; Bredbenner & Simon, 2019; Buljan et al., 2018; 2020a: 2020b; Kerwer et al., 2021; Raynor et al., 2018; Santesso et al., 2015), typically measured using multiple-choice formats or open-ended questions. While limited by their focus on short-term outcomes, the findings showed that the format used and the way information is presented impact reader comprehension, with text-based PLSs being the most effective for knowledge translation. Not unexpectedly, PLSs have also been shown to be easier to understand than other sections of scientific manuscripts, including article abstracts. In the context of psychology, for example, a within-person design experimental study including 166 participants showed comprehensibility for a non-academic audience was higher for PLSs compared to scientific abstracts and that PLSs significantly increased understanding and knowledge of the article content (Kerwer et al., 2021).

While this body of research suggests that text-based PLSs can effectively convey the results of health and medical research, much of this work has been experimental in design. Less attention has been given to the adoption, implementation, and sustainability of PLSs. Examining these broader issues remains critical as PLS application into practice is still inconsistent and heterogeneous and encounters resistance on various fronts (Riganti & McKinnon, 2023).

Introduction and adoption of plain language summaries

In academic publishing, PLSs were first introduced in the late 1990s by health and medical journals as an optional component (Haughton & Machin, 2017). Although their adoption across academic publishing has increased since that time, not all journals publish PLSs, and amongst those that do, many do not make PLSs a mandatory part of the submission process (FitzGibbon et al., 2020). In 2017, for example, Haughton and Machin conducted a review of publishers representing 7630 medical journals and discovered only 1% of these journals published PLSs. A 2019 study (Carvalho et al., 2019) similarly investigated the extent to which records in the Physiotherapy Evidence Database (PEDro) – an online catalogue of evidence about physiotherapy interventions – included PLSs. Of the 34,444 records in PEDro, only 4421 (13%) had PLSs published in English. Over half (63%) of the records with a PLS were RCTs. More recently, Baróniková and colleagues' (2024) survey of journal editors and publishers found that 19 of 26 (73%) journals did not allow PLSs from authors. Despite the limitations of this study, including a non-random convenience sampling approach and small sample size, it usefully highlighted that the most common reasons given by editors and publishers for not publishing PLSs were the perceived lack of author and reader demand as well as perceived lack of relevance to the journal content (Baróniková et al., 2024).

Although there is variation in study design and quality across studies that have explored the adoption of PLSs to date, they paint a consistent picture of low uptake and adoption in academic publishing. Beyond academic journals, however, PLSs have also been adopted by research funding bodies, ethics committees and research organisations (Riganti & McKinnon, 2023). Such organisations have often mandated inclusion as part of an application for research funding or a clinical trial report to enable interest-holders, including reviewers, panel, board members and public members, to understand the application better when they are not subject matter experts. In such cases, there are often regulatory requirements to produce a PLS (Riganti & McKinnon, 2023). For example, the European Union Clinical Trials Regulation number 536/2014 requires clinical trial sponsors to release a 'lay summary' of the trial results (Barnes & Patrick, 2019). The National Institute for Health Research (NIHR) has taken a similar leadership role in ensuring that the findings of the research it funds are made accessible to a broad audience, mandating that all research applications to the NIHR must include a PLS (NIHR, 2021). Even very early research demonstrated much greater adoption of PLSs in such settings outside of academic publishing. Reporting on a 2012 BioMed Central survey of 50 researchers, Denegri & Faure (2013), for example, found that 75% reported that PLSs were needed when applying for ethics approval for their randomised controlled trial (Denegri & Faure, 2013). There is an implementation lag in the context of PLSs specific to academic publishing, warranting further investigation of the barriers and challenges in such contexts.

Accessibility, use and perceived value of plain language summaries

Beyond the adoption of PLSs by journals or publishing companies, significant challenges remain regarding their accessibility and the identification of their readership. Within academic journals, PLSs – like scientific abstracts – are typically included as part of the published manuscript. However, no standardised guidance on their placement within articles leads to inconsistencies across journals and publishing groups (Riganti & McKinnon, 2023). While FitzGibbon and colleagues (2020) reported that all but one journal in their study published the PLS alongside the corresponding research article and that PLSs remained accessible even when the main article was paywalled, broader discoverability remains limited. Except for those in the Cochrane Library, most PLSs are embedded within journal articles rather than stored in searchable, centralised repositories (Gunn, 2024). PLSs are challenging to locate using standard search engines such as Google without prior knowledge or the use of specific keywords.

A related challenge regarding the implementation of PLSs in health and medical publishing is that little is also known about the actual readership of PLSs. A recent survey of journal editors and publishers found that the primary readership of PLSs could be categorised into one of three groups: a) patients, patient organisations and patient advocacy groups; b) professionals in healthcare and research; and c) students (Bároniková et al., 2024). While Edgell & Rosenberg (2022) provide documented examples of the use of PLSs across each of these stakeholder groups gained through semi-structured qualitative interviews with five day-to-day users of PLSs from different stakeholder groups, very little work has been done to quantify access and understand the broad readership of PLSs. In 2021, Maurer and colleagues reported that Google Analytics on the US Patient-Centered Outcomes Research Institute's posted PLSs indicated nearly 29,000 views in the final quarter of 2019 (Maurer et al., 2021). However, it remains unclear whether the views were from patients, professionals or students, and while functional, similar analytics have not been made available by academic journals.

Given the limitations of data analytics, a substantial proportion of research on PLSs has focused on self-reported or intended use rather than objectively measured actual use. For example, Pushparajah and colleagues (2018) conducted a cross-sectional survey with 90 neurologists in the US. More than half (60%) said they would use PLSs with their patients, with only 13% saying they would not do so. Approximately half (46%) considered PLSs to be valuable, particularly with patients who have a rare disease or have been newly diagnosed with a serious illness, and saw the value of both online and printed versions of PLSs during appointments (Pushparajah et al., 2018). Lobban et al. (2022) similarly surveyed 103 healthcare professionals from the readership of two journals on type 2 diabetes. Approximately 71% of respondents rated PLSs as "very/extremely useful", and about half reported using them with patients and family members (Lobban et al., 2022). Hadland et al. (2025) surveyed 188 healthcare professionals. Most (73%) reported having read or contributed to at least one PLS, and 76% participants used the PLS to quickly understand the corresponding research article, with 32% stating they would use them with patients or advocacy groups to aid interactions or share them as an information source (Hadland et al., 2025). While collectively, these studies suggest the potential value of PLSs in consultations and as a resource for shared decision-making, they have limited generalisability as most have been conducted with a narrow range of healthcare professionals (usually a specific type of medical specialist, e.g., neurologist); limited data is available on the use of PLSs with general practitioners and allied health practitioners such as nurses, physiotherapists and dietitians. Actual use within consultations may also be different to self-reported use.

Consumer perspectives of PLSs are also relatively limited. The previously mentioned 2022 systematic review, for example, identified several studies that assessed perceived understandability, user experience and ease of use of specific PLSs (Stoll et al., 2022). Another body of research has focused on discrete formats or design features of PLSs. For instance, Kerwer et al. (2021) surveyed 166 university students and asked for their opinions about PLSs, both with and without subheadings. Much less research has been dedicated to understanding patients' and consumers' broad perceptions of PLSs as a health communication tool or their experiences using PLSs within or outside of healthcare consultations. In addition to examining provider perspectives, the study by Pushparajah and colleagues (2018), for instance, also explored the perspectives of patients who had been diagnosed with a chronic disease, finding that almost all (96%) patients were interested in sharing newly found health-related information with their doctor but that 45% noted they would only do so if they understood the information enough to have a conversation about it. This study did not examine patients' actual engagement with PLSs. Earlier, Nunn and Pinnfield (2014) conducted a qualitative study to understand better people's viewpoints and attitudes towards PLSs produced by health and medical journals, including 'lay participants' (Nunn & Pinnfield, 2014). They found that lay participants had concerns about the potential for bias in PLSs unless it was produced by an organisation such as Cochrane or NHS Choices, as well as concerns over the ethical use of PLSs if used by researchers or journals to falsely represent engagement with the public about their research (Nunn & Pinnfield, 2014). Together, these findings highlight a gap in the literature regarding how consumers use and interpret PLSs in real-world settings, underscoring the need for further research that examines both preferences and practical engagement and impact.

Writing plain language summaries: responsibility, training and guidelines

Exploring authorship of plain language summaries

Related to the implementation and uptake of PLSs in health and medical publishing, a body of literature has explored the roles, responsibilities and perceived feasibility of different authorship models. In the context of scholarly publication, PLSs are usually written by the author of the corresponding research article (Stricker et al., 2020). However, the feasibility of PLSs being produced by journal editors or in-house medical writers has also been examined. When analysing the characteristics of PLSs from 11 biomedical journals, for example, FitzGibbon and colleagues (2020) found that 9/11 journals identified that it was the responsibility of the researcher(s) associated with the research article to write the PLS. Less commonly, editors or editorial teams have been identified as responsible for producing PLSs (FitzGibbon et al., 2020). However, Kirkpatrick and colleagues' (2017) qualitative study concluded that it is not feasible for editors to produce PLSs in the quantity needed; participants felt the issue was one of achieving the best balance between cost and quality. Beyond this, however, editors' views about PLSs have rarely been explored.

As another alternative, in 2013, BioMed Central – a portfolio of 160 journals in the area of medicine – sought to investigate the feasibility of providing an in-house service for writing PLSs, paid for by the research team (Denegri & Faure, 2013). After contacting 200 researchers and 370 BioMed Central editorial board members, they received only 50 responses, of which most (79%) respondents indicated that they would not pay or were unsure about paying to have their PLS written in-house (Denegri & Faure, 2013). Beyond cost limitations, the efficacy of this publishing model was also explored by Kirkpatrick and colleagues (2017). Using existing PLSs in the NIHR journals library, Kirkpatrick and colleagues (2017) asked authors to re-write PLSs based on additional guidance. They asked a professional writer to edit the same PLS (Kirkpatrick et al., 2017). These PLSs were assessed by 60 public reviewers and compared to the original PLSs (Kirkpatrick et al., 2017). Overall, the edited versions were found to be easier to read than the originals; however, there was no significant difference between those edited by the researcher and those edited by the medical writer (Kirkpatrick et al., 2017). Study participants commented on specific aspects of the PLSs, i.e., sub-headings helped to break up the text and the importance of reducing jargon (Kirkpatrick et al., 2017). Based on these combined findings, researchers appeared well-placed to continue producing PLSs for their published work; however, they could benefit from additional support in the form of precise and detailed guidance for writing PLSs. This study did not assess the added benefit of obtaining input from interest-holders such as patients or other public members on the perceived quality of PLSs.

Training to support researchers in writing plain language summaries

Despite the promising results of Denegri & Faure (2013), which suggest equivocal performance of authors and professional writers in developing PLSs, writing a PLS requires skills different to that of more formal academic writing, and some researchers can struggle with the transition (Salita, 2015). Researchers are not generally taught PLS writing skills; most journals do not offer specialised PLS writers or editors (Wada et al., 2020). Brownell and colleagues (2013) suggest that it is essential to teach science undergraduates and graduates the skills needed to enable them to effectively communicate with a non-expert audience, arguing for the inclusion of a course on science communication to be included in the curriculum. While there have been broad acknowledgments that skill development and training are needed to support researchers in writing PLSs (e.g. Nunn & Pinnfield, 2014; Smith & Ashmore, 2010; Wada et al., 2020), there are no such training programs specific to PLSs reported in the academic literature. For researchers wanting to develop greater expertise in writing PLSs, online PLS toolkits and resources are the best place to start (e.g., Australian Clinical Trials Alliance, 2025; Envision the Patient, 2025; NIHR, 2021).

The role of plain language summary guidelines and instructions

As an alternative to training and supporting authors in developing PLSs, several organisations and independent authors have published criteria, tips, and best practices for writing PLSs. (e.g., American Psychological Association, 2025; Cumpston et al., 2022; Envision the Patient, 2025; NIHR, 2021; Tanock, 2021; Zarshenas et al., 2023). Journals also increasingly include instructions for writing PLSs, usually located within the author instructions for the journal. Reviews of these instructions to date have noted their heterogeneity, with variation in length, content and the amount of detail they include (Haughton & Machin., 2017; Narayanan et al., 2018). Haughton and Machin (2017), for example, conducted a review of publishers representing 7630 journals from a range of disciplines, including science, medicine and economics. Of the 69 (≤1%) journals that published a PLS, there was minimal guidance and wide variation in instructions to authors regarding the structure and content of the PLSs (Haughton & Machin, 2017). However, since these findings are only available from a poster presentation, limited detail is available, particularly regarding the study methodology that might provide context for the study results.

Peer-reviewed articles have provided a narrower and more selective overview of author instructions for writing PLSs. Narayanan and colleagues (2018), for instance, reported on author instructions for writing PLSs in 26 out of 30 reviewed journals. Consistent with the findings of Haughton and Machin (2017), they found that journals provided limited instructions for writing PLSs, including only maximum word count or length and the desired structure (e.g., bullet points, single paragraph or inclusion of sub-headings). Few reported elements beyond length and structure, including guidance concerning health literacy principles such as using plain language, limiting or avoiding jargon, or limiting passive sentences (Haughton & Machin, 2017). FitzGibbon and colleagues (2020) similarly investigated the characteristics of PLSs from 11 biomedical journals. Word limits varied considerably from 60-80 to 500 words; however, the study did not investigate paragraph structure further, such as the recommended use of bullet points or sub-headings (FitzGibbon et al., 2020). There was also a consistent lack of clarity regarding the target audience of PLSs. Some journals specified the target audience for the PLS should have expertise equivalent to an undergraduate degree in a non-related science field. In contrast, others noted the target audience was a non-expert, i.e., "interested persons without a scientific background" or a "non-medical audience" (FitzGibbon et al., 2020). The scope of the study did not extend to examining the health literacy principles or content (FitzGibbon et al., 2020).

Independent online resources are also available to support authors in developing PLSs, not affiliated with specific journals or publishing companies. One example is that produced by the stakeholders from the Patients Participate! Project and United Kingdom Office for Library and Information Networking (UKOLN). This group reviewed 14 sets of instructions for writing PLSs published by consumer advocacy groups, patient organisations and academic sources, and their recommendations were used to compile a practical guide for writing PLSs (Duke, 2012). Other examples include the 'How-To' guide developed by Patient Focused Medicine Development, a working group comprised of interest-holders with experience in patient engagement and PLSs (Dormer et al., 2022) and the guide for the co-design and development of PLSs developed by Wada and colleagues in 2020 (Wada et al., 2020). However, at present, no study has evaluated these PLS writing guides and resources, rendering it impractical to directly determine the impact that they have had on researchers in terms of influencing how they write PLSs or to explore their uptake and adoption.

In a similar effort to standardise instructions for writing PLSs, Open Pharma – a "multi-sponsor collaboration of pharmaceutical companies, non-pharmaceutical funders, publishers, patients, academics, regulators, editors, and societies" (Rosenberg et al., 2021) – proposed a set of minimum standards for PLSs to be adopted industry-wide by all medical journal publishers for PLSs. The intention is that this minimum standard would function as a starting point for researchers and that such standardisation will increase the accessibility, suitability and discoverability of PLSs (Rosenberg et al., 2021). While the intended industry's broad adoption of standardised instructions for writing PLSs may be a positive step towards uniformity, no data is available to measure the uptake or impact of such recommendations and guidelines. There remains a clear gap in the literature regarding how authors adhere to journal instructions for preparing PLSs or independent guidelines and recommendations such as those from the Patients Participate! Project and Open Pharma. Without systematic evaluation of author compliance, it remains unclear whether current instructions are sufficiently clear, feasible, or effective in guiding authors to produce summaries that meet the needs of non-specialist audiences. This lack of governance represents a critical barrier to improving the quality and impact of PLSs across the scientific literature.

Plain language summaries and health literacy principles

Plain language summaries are intended for use by a non-expert public, ideally without jargon (NIHR, 2021). Several empirical studies to date have investigated the readability of PLSs, of which a commonly expressed concern is the high-grade reading level of PLSs and the overuse of jargon, indicating many published PLSs may not be suitable for a general audience (Anderson et al., 2021; Barnfield et al., 2017; Carvalho et al., 2019; Ferrar & Conran, 2021; Karacic et al., 2019; Kirkpatrick et al., 2017; Rakedzon et al., 2017; Raynor et al., 2018, Rees et al., 2017; Silvagnoli et al., 2022; Stricker et al., 2020; Wen & Yi, 2024). To measure these outcomes, researchers have, for example, computed readability indices such as the Flesh-Kincaid Grade Level (Carvalho et al., 2019; Ferrar & Conran, 2021; Karacic et al., 2019; Silvagnoli et al., 2022; Stricker et al., 2020) or asked participants to self-report whether information was easy to find in a PLS (Anzinger et al., 2020). Using the former methodology, for example, in a 2019 study with 4421 PLSs, the average readability scores showed that the PLSs were written at a more advanced level than recommended for a general audience (Carvalho et al., 2019). Using the Flesh-Kincaid Grade Level, the average was 16, well above the pre-defined study threshold of grade 10 (Carvalho et al., 2019). Similarly, Wen & Yi (2024) reviewed 37,100 pairs of abstracts and PLSs from six biomedical journals, analysing the readability and level of jargon in both. On average, abstracts were written at higher reading levels and contained more jargon than PLSs, which is aligned with similar research in other fields and disciplines (e.g. Liu & Li, 2024; Wen & Yi, 2024). However, PLSs were still written at a higher reading level and with more jargon than is recommended for a general audience (Wen & Yi, 2024).

From these studies, we can conclude that researchers consistently write PLSs using jargon and at reading levels above that recommended for a general audience. However, little research has explored the reasons for this or the implications from the perspective of PLS readers. Studies that have engaged directly with readers highlight essential challenges. For example, participants in the study by Nunn and Pinfield (2014) reported that PLSs sometimes employed language they perceived as "patronising" and noted the inherent difficulty of crafting summaries catering to all readers' diverse needs. Similarly, in the Silvagnoli et al. (2022) survey, most respondents preferred text-based PLSs written at a medium-complexity level. These findings suggest that while readers value clarity, they also recognise the challenge of balancing simplicity with sufficient detail to meet varying informational needs. Notably, while the Open Pharma recommendations acknowledge the need for accessibility, they do not prescribe a specific readability threshold, allowing flexibility to address the heterogeneous nature of PLS audiences (Rosenberg et al., 2021).

Consumer involvement

In line with the increasing recognition of the importance of involving end users of research, this has become a growing field of interest, with several studies exploring this area (Dormer et al., 2022; Kerwer et al., 2021; Kirkpatrick et al., 2017; Nunn & Pinnfield., 2014; Pushparajah et al., 2018; Silvagnoli et al., 2022; Wada et al., 2020). In the spirit of "no evidence about me, without me" (Walker et al., 2021), the co-creation of PLSs involves collaboration between researchers and public and patient partners in developing PLSs. Several projects have successfully demonstrated the effectiveness of such collaboration (e.g., Barnfield et al., 2017; Wada et al., 2020). However, the extent to which this concept has been adopted and implemented by researchers in practice is unclear. In 2013, Denegri & Faure reported on a survey conducted by BioMed Central in which most (79%) researchers surveyed did not involve a 'lay' person in the production of their PLS and did not think it was necessary because PLSs are "not difficult to write". A 2020 review of author instructions for PLSs found only one journal suggested that researchers consult a patient or consumer representative for assistance (Fitzgibbon et al., 2020). It would be helpful to understand better the reservations of researchers to involve the public or other interest-holders in PLS co-creation to develop solutions to accommodate or overcome them and increase collaboration in PLS development. Researcher attitudes towards PLS co-creation may have altered since Denegri & Faure's 2013 survey.

Aims, scope and structure of the thesis

This thesis focuses on aspects related to the production, publication and dissemination of PLSs in health and medical journals and aims to: 1) provide an understanding of the author instructions for writing plain PLSs in health and medical journals (Chapter 2); assess the level of compliance of PLSs to their author instructions in health and medical journals (Chapter 3); obtain an understanding of what is most important to people who read PLSs, specifically those with chronic medical conditions (Chapter 4); and gain knowledge about the perspectives of editors of health and medical journals on the production, publication and dissemination of PLSs (Chapter 5). The overall goal is to contribute to understanding how PLSs are perceived by interest-holders, leading to an optimisation of PLSs to deliver accessible research to a broad and diverse audience.

In terms of methodology, the studies in this thesis were primarily exploratory in nature, aiming to address novel research questions. I employed a sequential multi-methods research approach throughout the thesis. The studies in Chapters three, four and five were developed iteratively, informed by findings of each previous stud, in addition to developments in the field of PLSs.

As this thesis demonstrates, many health and medical journals do not publish PLSs. Due to the length or nature of some studies, the journals selected were chosen even if they did not publish PLSs. To align with the findings of this thesis and showcase best practice, I developed a PLS for each study, even when not required by the journal. For Chapter 4, the PLS was sent to study participants in accordance with ethics requirements. PLSs were also used to promote the study on social media platforms such as X (formerly Twitter), Blue Sky and LinkedIn. The PLS for each study is included with its corresponding manuscript, along with any other summary required by the journal e.g., Article Summary.

Chapter Summary

Although first introduced to scholarly publishing in the late 1990s, it is only in recent years that text-based plain language summaries (PLSs) have grown in popularity in more recent years, with an appreciation of the valuable role they play in providing accessible and reliable research to a diverse audience, assisting to combat the spread to health misinformation. Beyond their publication in academic journals, PLSs are widely used by funding bodies, ethics committees and research organisations. Despite their value to many interest holders, challenges remain regarding the accessibility and identification of their actual readership. Surveys suggest that PLSs are valued by physicians and patients, particularly those with chronic medical conditions, in a shared decision making context. PLSs are traditionally written researchers i.e., the author of the corresponding article, and feasibility studies suggest this approach achieves the best balance between cost and quality. Research suggests that researchers could benefit from more training and support in writing PLSs. Although journals provide author instructions or guidelines to detail how to write a PLS, reviews note that these instructions vary between publishing groups with a high degree of heterogeneity. Efforts exist to standardise PLS guidelines, however, no evaluation of this approach has been conducted. Lacking also is an understanding of author adherence to these guidelines. Aimed largely at non-exerts, studies indicate that PLSs contain high levels of jargon and are frequently written at reading levels high than is recommended for a general audience. Involving end-users of PLSs in their development could help address this concern, however, despite the clear benefits of such involvement, the extent to which this has been adopted in practice is unclear.

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Chapter 2. What author instructions do health journals provide for writing plain language summaries? A scoping review

This chapter reports a scoping review of the author instructions for writing PLSs in health and medical journals. The study aimed to achieve a more thorough understanding of these instructions for writing PLSs, which is intended to be a step towards advancing evidence-based, consistent instructions for authors.

As discussed in the Introduction, author instructions for PLSs have been previously explored and reported by several authors; however, such studies have been small in scope and the level of detail reported. The study in this chapter builds on previous work, with the advantage of providing a detailed exploration of author instructions for PLSs, reporting on eight elements in the instructions, some not previously considered by other studies, e.g., the use of resources.

Since the data for this study comprised grey literature, as it would be obtained from journal websites, and due to the study's exploratory nature and the type of data involved, a scoping review was determined to be the most suitable methodology. I accessed guidance from the Joanne Briggs Institute (JBI) on best practices for conducting scoping reviews along with Grant & Booth (2009), and reported using the PRISMA extension for scoping reviews (PRISMA-ScR) checklist.

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Abstract

Background: Plain language summaries (PLSs) are intended for a non-expert audience to make health research accessible and understandable to the public. Since most research is written with jargon and at a high reading level, PLSs have a key role to play in health communication. However, there is a high degree of variability in the instructions for writing PLSs, which may impede their usefulness as a tool for communicating health research to the public.

Objective: This scoping review aimed to analyse the author instructions for PLSs provided by leading biomedical and health journals.

Method: We screened 534 health journals covering 11 categories selected from the InCites Journal Citation Reports linked to the top 10 non-communicable diseases. We included journals published in English that recommended the inclusion of a PLS (as defined by the National Institute for Health Research) and provided authors with text-based instructions on how it should be written. Two independent reviewers extracted data about common elements identified in author instructions, such as word count/PLS length, content, structure, purpose, wording to support plain language, and the use of jargon, acronyms and abbreviations. Other aspects of PLSs were recorded, such as the label used (e.g., plain language summary, lay summary, and patient summary), journal publisher, consumer involvement and whether the PLS is optional or mandatory. We recorded the frequency of each element and qualitative details of specific instructions. A consumer representative provided ongoing and iterative feedback on the methods, results, and reporting of this study.

Results: Despite reviewing 534 journals across 10 non-communicable disease areas and 11 journal categories, we found only 27 (5.1%) contained text-based instructions for PLS. Most of the 27 journals included in this review (70%) did not require a PLS. Approximately 70% of journals with PLS instructions included advice about the use of jargon, abbreviations, and acronyms. Only one journal recommended using a readability tool; however, five noted that the audience's reading level or readability of the PLS should be considered. Author instructions were highly heterogeneous between journals. There was inconsistency regarding the word count/PLS length (e.g., between 100 and 850 words), structure (e.g., paragraphs or bullet points), and varying levels of detail for other elements in the instructions. Although only one journal recommended consumer involvement in the development of PLSs, many recommended authors consult those who are not experts in their field to review their summary before submission.

Conclusion : The development of consistent author instructions could enhance the effectiveness and use of PLSs. Such instructions should be developed with consumers to ensure they meet the needs of a lay non-expert audience.

Key Points for Decision Makers

- In this review, we searched 534 biomedical and health journals and conducted a detailed analysis of their author instructions for writing plain language summaries (PLSs).
- Only 27 journals (5.1%) met our inclusion criteria, in that they had author instructions for writing PLSs aimed at a lay non-expert audience.
- We found variation between journals in the content and detail of instructions provided, for example the word count/PLS length, content, structure and recommendations regarding the use of jargon in the author instructions for PLS.
- PLS could be improved with consistent instructions developed with the assistance of consumers.

Plain language summary

Plain language summaries (PLSs) are short summaries of research articles written in clear, easy-to-understand language. This makes them a useful way of getting health research to a non-expert reader. Many journals suggest authors write a PLS with their article, but the instructions for them vary from journal to journal. The aim of this study was to review the author instructions for writing PLSs from health journals. We looked at 534 journals and only found 27 (5.1%) had a PLS aimed at a lay reader. We looked at the author instructions from these 27 journals and noted common details of a PLS. For example, we checked word count/PLS length, content, structure, and wording. We also recorded the label used, publisher and whether the PLS was required or not. We found most (70%) journals did not require a PLS. The instructions were different from journal to journal. For example, word count/PLS length ranged from 100 to 850 words and the suggested structure was a mix of paragraph format and bullet points. About 70% of journals gave advice about the use of jargon, abbreviations and acronyms. Only one journal suggested the use of a readability tool, but five thought the reading level of the reader or readability of the PLS was important. Only one journal suggested consumers be involved in writing a PLS, however many suggested the PLSs be checked by someone who is not an expert in the field. PLSs could be improved with help from consumers to make instructions that are more standard.

Introduction

Most health research is not written with the public in mind as it contains jargon and acronyms and is usually written at a high reading level (Wada et al., 2021). Plain language summaries (PLSs) are condensed summaries of research articles written in plain, easy-to-understand language aimed at a non-scientific audience (Wada et al., 2021). Ideally, PLSs contain no jargon or technical language (NIHR, 2021), which makes them an ideal tool for disseminating reliable health information in a way that a lay audience can understand (Nunn & Pinnfield, 2014). PLSs are particularly important in making decisions for people with chronic health conditions (Pushparajah et al., 2018). This audience considers journals a valuable source of information about their health condition, using information from journal articles to inform health decisions (Pushparajah et al., 2018).

Scientists are accustomed to describing their work using jargon and technical concepts, and they may find it challenging to explain their research in a way that is accessible to a non-expert lay audience (NIHR, 2021). To guide authors, many journals and organisations provide instructions for writing PLSs.

However, the level of guidance they provide varies, and the advice is not always clear and/or thorough (Kirkpatrick et al., 2017). Despite the availability of instructions for writing lay summaries, research suggests that most PLSs are difficult for consumers to understand Carvalho et al., 2019; Rakedzon et al., 2017). As such, they may misinterpret the messages they contain (Wada et al., 2021). Journals should provide clear instructions to guide the author to write the PLS with the intended audience in mind. Such instructions could include avoiding jargon and using accessible language (Wada et al., 2021). Another strategy is recommending the PLS be reviewed by a member of the lay public. This could help build capacity and confidence in the lay public through active participation in the research process (NHMRC, 2016).

Previous reviews of PLSs and the author instructions for writing them have been conducted; however, they report limited findings and often in minimal detail (Duke, 2012; Haughton & Machin, 2017; Narayanan et al., 2018; Shailes, 2017). One review focused primarily on PLS author instructions from consumer advocacy groups, including only one list of instructions from a scientific paper and one published by a university (Duke, 2012). Another review of PLS author instructions included over 50 data sources, such as journals and scientific organisations (Shailes, 2017); however, the only element of PLS author instructions noted was word count/PLS length (Shailes, 2017).

This review aims to provide a better understanding of the PLS instructions currently available to authors. We see it as an important step in developing evidence-based, consistent, uniform instructions for writing PLSs. Although further research is needed to determine what those instructions should include, a thorough understanding of the situation and potential challenges to address is vital.

Methods

Protocol and registration

This review was conducted according to the Joanna Briggs Institute Reviewers' Manual for scoping reviews (Aromataris & Munn, 2020). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews (PRISMA-ScR) (Tricco et al., 2018) was used as a guide. The protocol for this review was completed before data analysis and is registered on Open Science Framework (Gainey et al., 2019).

Information sources and search

In a pilot scoping review conducted by our team, our information sources included journals, global health organisations (e.g., WHO), professional associations and multidisciplinary organisations, consumer advocacy groups, and funding bodies. Of those that published PLSs and author instructions for writing PLSs, 79% were journals. Although organisations such as those included in our pilot are stakeholders in the area of PLS, they are not high producers of PLSs and PLS instructions. Therefore, we decided to limit our information sources to journals for this review.

As previous reviews that investigated PLS author instructions were limited in scope and number of journals searched, we designed this study to comprehensively analyse many high-impact health journals. We developed our search strategy to ensure we analysed many journals from various health areas. We determined that the top 10 non-communicable diseases responsible for the greatest burden of disease (Institute for Health Metrics, 2020) was an appropriate framework to apply. Diseases from these categories tend to be chronic, and we know from previous research that people with chronic diseases or illnesses are high users of health information, which lists journals as one of the top three preferred sources of health information (Pushparajah et al., 2018).

We searched biomedical and health journals from 11 journal categories selected from the InCites Journal Citation Reports. Journals from the category of medicine (general and internal) were added to increase the scope of our search. Using data from the 2020 Incites Journal Citation Reports, we compiled a list of 50 journals for each journal category, selecting those with the highest impact factor. Through a priori consensus, we decided that searching 50 journals in each category according to impact factor was a systematic way of approaching our search and would provide sufficient depth and coverage. The category of Rheumatology only had 34 journals that met our inclusion criteria, giving us a total of 534 journals searched. We compiled our list of journals on 18 August 2021. Non-communicable diseases and journal categories, with the number of each journal per category, are outlined in Table 1.

Table 1. Journal categories and corresponding top 10 non-communicable disease categories

Non-communicable disease category *	**Journal category**	**Journals**
Not applicable	Medicine, General & Internal	50
Cardiovascular disease	Cardiac and cardiovascular systems	50
Neoplasms	Oncology	50
Musculoskeletal	Rheumatology	34
Mental Disorders	Psychology	50
Diabetes and Chronic kidney disease	Urology & Nephrology	50
Chronic respiratory	Respiratory system	50
Neurological disorders	Clinical neurology	50
Digestive diseases	Gastroenterology & Hepatology	50
Sense organ diseases	Ophthalmology	50
Skin diseases	Dermatology	50
Total		**534**

* Based on category listings from the Incites Journal Citation Reports as at 18/08/2021 (Clarivate, 2020).

Information selection: Inclusion criteria

We included journals published in English that recommended the inclusion of a PLS and provided authors with instructions on how it should be written. We identified a PLS as being a summary of a research article that is not the abstract and is in alignment with the National Institute for Health and Care Research (NIHR) definition of a PLS, which states, "A plain English summary is a clear, brief summary of the research that has been written for members of the public, rather than researchers or professionals. It should be written clearly and simply, without jargon and with an explanation of any technical terms" (NIHR, 2021). We excluded the following: (1) Journals that recommend using a PLS but do not include any information on how the PLS should be written in their author instructions. These were excluded because our review was focused on an analysis of the author instructions for PLSs, and the information contained within them comprised the data for our study, (2) Journals that recommended a PLS but only provided a link to a third-party service that provides authors with a PLS for a fee, and (3) Other formats for PLSs, such as graphical and video, as these formats are a reasonably new option for authors and are offered in addition to text-based PLSs.

Information selection: screening

To determine the intended audience for the PLSs, one reviewer (KG) screened the author instructions of all 534 journals in October 2021 and recorded the intended audience. A journal was included if the author instructions described a PLS's intended audience with labels such as consumer, public, patient, lay, people living with 'X' (e.g., people living with diabetes), or similar. A second reviewer (JS) checked a random sample of 10% of journals from each journal category to ensure reliability. This sample was selected using a random number generator on 20 October 2021. Any conflicts were resolved through discussion.

Data extraction and charting

We conducted a pilot study to revise our data extraction and charting strategy. We inspected the author instructions for writing PLSs and noted components or 'elements' and features or 'characteristics' that were common across many journals. We defined 'elements' as aspects in the author instructions that guide authors on how to write the PLS and how it should appear. We identified elements such as word count/PLS length, structure, purpose, content, wording to support plain language, guidance on using jargon, acronyms and abbreviations, and resources for writing a PLS. We defined the 'characteristics' of a PLS as those items in the author instructions that related to a PLS but were not elements. These were the label used for the PLS (e.g., 'patient summary', 'lay summary'), whether the PLS was mandatory or optional for each journal, and any recommendations for consumer involvement in developing the PLS. We also recorded the journal publisher to note any patterns in journals published by the same group and the term used by the journal to designate their author instructions/submission guidelines. We refer to these throughout as 'author instructions'. Aspects of PLSs not covered by other categories were grouped under the heading of 'miscellaneous'. These included the option to use graphical PLS/abstracts, images, whether the PLS is freely available to readers (i.e., no paywall), whether the journal translated PLSs into languages other than English, and information about the empirical foundation on which PLS author instructions were developed. Using an iterative and inductive process, reviewers also extracted any other information about PLSs they discovered and determined to be relevant.

Reviewers noted links to two kinds of resources for writing PLSs: one written by the journal and one from a third-party source. For example, some Elsevier journals linked to one of their own resources titled "In a nutshell: how to write a lay summary" (Tanock, 2021) and journals from multiple publishers provided a link to the plain English summaries resource published by the NIHR (NIHR, 2021). We only collated data from resources provided by the journal itself, not third parties. This is because it is reasonable to expect an author will consult all instructions for writing a PLS provided directly by the journal itself. In contrast, third-party resources may only be consulted if the author wants extra guidance.

Author instructions varied, and not all journals provided information on each element; therefore, we recorded the frequency of each item and qualitative details of specific instructions. During November and December 2021, two reviewers (KG and JS) independently extracted data, each reviewing 50% of the author instructions of the included journals. Reviewers checked each other's data and resolved conflicts through discussion. The coding framework and data charts were developed throughout the data collection and analysis process. Changes were made to ensure both were capturing all qualitative and quantitative data relevant to the study aims. We tested our data charts during piloting and developed them using an iterative process until finalised.

Consumer involvement

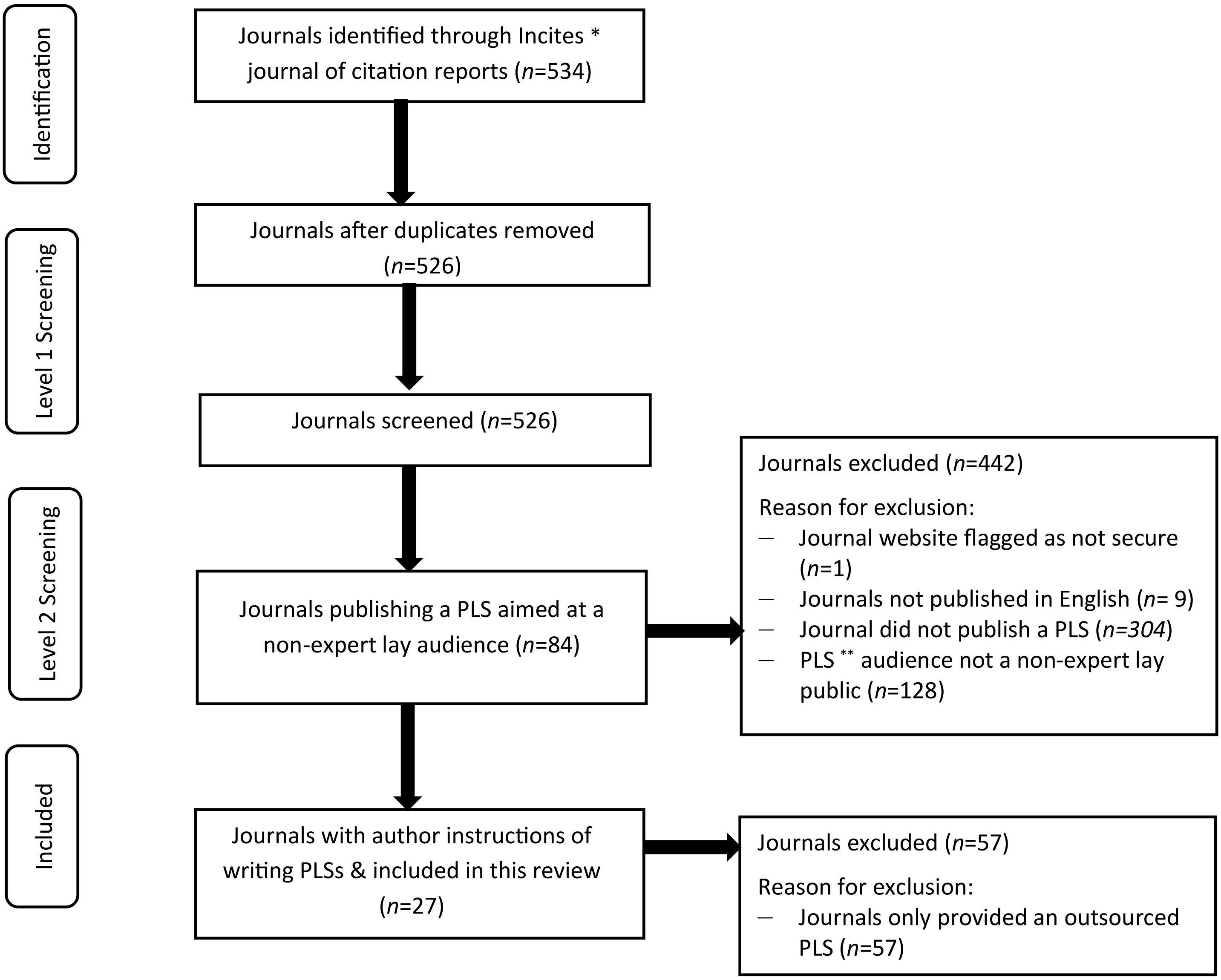
We consulted a consumer representative (SC), who was engaged as part of the research team, to provide input on the study. SC provided ongoing feedback on the study methods and results, offering insight from the perspective of an end-user of PLSs. Specifically, SC helped with the iterative development of the data charts and contributed to the discussion section of the manuscript, suggesting changes to improve clarity. SC also reviewed the full manuscript and co-wrote the PLS for this review.

Results

Selection of sources of evidence

We identified 534 journals through the 2020 Incites Journal Citation Reports. After screening, 27 (5.1%) journals met our inclusion criteria in that they contained author instructions for writing PLS, published by six different publishing groups (see Figure 1). Table 2 provides a breakdown of the key characteristics and Table 3 a summary of the elements included in author instructions for PLSs. A PLS was mandatory in 8 (30%) journals and optional in 19 (70%) journals. We found three labels used to designate a PLS: plain language summary, lay summary, and patient summary. About half (51.9%) of journals used the terms guidelines or guide when referring to their author instructions, while the second most common term was 'instructions' (33.3%). Only one journal recommended the involvement of consumers in the development of PLSs. However, several (11, 40.7%) journals recommended that PLSs be reviewed before submission, for example, by someone without knowledge of the subject area. Only one journal (Cochrane Database of Systematic Reviews) provided information on developing their instructions for writing PLSs.

Figure 1. Selection of sources of evidence



[*] Incites journal of citation reports 2020 (Clarivate, 2020)

[**] PLS = Plain language summary

Table 2. Characteristics of plain language summaries from author instructions

Characteristic of plain language summaries	**Frequency (*n=27*)**
Publisher	
Elsevier	9 (33.3%)
Springer Nature	7 (25.9%)
Taylor & Francis	4 (14.8%)
Wiley	3 (11.1%)
SAGE	2 (7.4%)
Dove Medical Press	2 (7.4%)
Term for author instructions	
Submission guidelines/Guide for authors	14 (51.9%)
Instructions for authors/Author instructions	9 (33.3%)
Author information	3 (11.1%)
Handbook	1 (3.7%)
Inclusion	
Optional	19 (70.3%)
Mandatory	8 (29.6%)
Label	
Plain language summary	18 (66.7%)
Lay summary	5 (18.5%)
Patient summary	4 (14.8%)
Recommended consumer involvement	
Role in co-writing PLS	1 (3.7%)
Role in reviewing PLS	11 (40.7%)
Miscellaneous	
Graphical PLS/abstracts	11 (40.7%)
Freely available to readers	5 (18.5%)
Inclusion of images recommended	2 (7.4%)
Translated into a language other than English	2 (7.4%)
Information on the development of PLS author instructions	1 (3.7%)

Elements in author instructions for plain language summaries

Table 3 provides a description of elements in the author instructions for PLSs along with selected examples to illustrate the diversity of findings.

Audience: The intended or potential audience of the PLS was noted in all 27 journals. The audience was expressed as lay, patient, caregiver, consumer, or public in 22 journals and expressed as non-medical/non-academic in 14 journals. Other nominated audiences included non-specialist researchers (five journals), clinicians (six journals) and stakeholders, such as decision-makers, journalists, and funding bodies (seven journals).

Word count/length: We found a reference to the word count or length of the PLS in the author instructions all 27 journals. It was expressed as a numerical value (e.g., up to 'X' words) in 20 journals and as a suggested length (e.g., two to three short sentences or a short paragraph) in seven journals. In two journals, the word limit was up to 100 words; in 14 journals, it was up to 250 words; in three journals, it was up to 300 words; and in one journal, it was up to 850 words.

Structure: We found 26/27 journals that referred to the structure of the PLS, with some making more than one suggestion relating to the structure. In 25 journals, the suggested structure was short sentences, a single paragraph in 11 journals, bullet points in six journals, and headings or suggested questions to answer in four journals. For example, "The structure of a lay summary should answer the main questions of 'who/ what/where/when/how many/why?'" (JACC: Cardiovascular Imaging).

Content: Specific information about the content of the PLS was found in all 27 journals. The amount of detail varied between journals, with 14 providing a low level of detail and 13 providing a high level of detail. A low level of detail was defined as a basic one-sentence instruction, e.g. "*Summarising the main message of the article*" (Journal of Hepatology). A high level of detail was defined as multiple points, questions or details to include. For example, the journal Therapeutic Advances in Musculoskeletal Disease included the following: "*Define the who, what, why, when, where and how of the research. Answer the following questions: Why was this study done, What did the researchers do? What did the researchers find and what do the findings mean? Ensure that your conclusion/take-home message is clear. The PLS should be a true reflection of the research presented, written in an engaging and accessible way, without exaggeration. Both merits and limitations should be discussed*". In three journals, content was prompted by suggested questions, such *as "Why was the study done?" "What did the researchers do and find?" "What do the results mean?" and "What is the objective influence on the wider field? "*(Postgraduate Medicine).

Purpose: Most journals (24/27) referred to the purpose of the PLS. As with content, the level of detail for purpose varied between journals. We found a low level of detail (1-3 sentences) in 12 journals and a high level of detail (at least 2-3 paragraphs) in 12 journals. The stated purpose varied from broad descriptions such as "Describe your findings" (European Urology Oncology) to those focusing on the importance of the PLS as a tool for researchers to communicate their findings to a broader audience, e.g*., "an effective tool to summarise your paper, extending the reach and impact that the paper can have, and making it accessible to a wider audience."* (Rheumatology and Therapy).

Wording: We found references to the PLS's specific wording or writing style in 25 of 27 journals. Using plain English or simple language was referred to in 23 journal instructions. Sixteen journals recommended using active rather than passive voice, and four suggested writing in the first person. Person-centred language (rather than focusing on illness or disability) was mentioned in seven journals, and positive language was used in four. Language that considered a lay non-expert audience was recommended, with 10 journals suggesting the writer of the PLS should use "language that does not patronise the reader". Five journals suggested the audience's reading level or the PLS's readability should be considered, and one suggested using a readability tool. Seven journals recommended using neutral or objective language or factual statements rather than opinions. Three journals suggested using *"interesting"* or *"engaging"* language. Examples *included "The plain language summary should be distinct from the abstract and should be written in an accessible, interesting way without spinning or exaggerating the story"* (Journal of Asthma and Allergy) and *"written in an engaging and accessible way, without exaggeration"* (Therapeutic Advances in Gastroenterology). One journal noted *"findings that readers might find upsetting, controversial or disappointing. When this is the case, we encourage you to follow the guidance about handling findings sensitively in the Dissemination checklist, item 15."* (Cochrane Database of Systematic Reviews).

Jargon, Acronyms and Abbreviations: A total of 19 out of 27 journals recommended that jargon should be avoided or explained when necessary. Sixteen journals suggested abbreviations be avoided or described before they are used. However, no journals suggested acronyms should be explained or avoided.

Resources: We found references to additional resources in the PLS writing instructions of 19 of 27 journals. Resources included short articles with tips on how to write a PLS and example PLSs. We located 14 resources written by the journal itself and seven from third parties, such as the PLS guidance resource published by the NIHR (2021).

Table 3. Elements of plain language summaries from author instructions

Element	Description	Frequency	Example(s)
Audience	Stated audience.	27 (100%)	“Non-medical audience” [a]
			“Non-specialists in the field, including members of the public and non-academics.” [b]
Word count/length	Maximum word count/length.	27 (100%)	“Two or three short sentences” [c]
			“No more than 250 words” [d]
Structure	How the summary should be structured.	26 (96.3%)	“3 brief bullet points” [e]
			“Formatted as a single paragraph.” [f] “Should be short, clear sentences broken up into relevant sections” [f]
Content	The information that should be included in the summary.	27 (100%)	“Provide an accurate representation of the article.” [g] “The summary should be based on the abstract of the paper.” [g]
			“Descriptions of the paper that are easily understandable.” [h] “True reflection of the research presented.” [h] “Both merits and limitations should be discussed.” [h] “Define the who, what, why, when, where and how of the research. Provide answers to the following questions: Why was this study done?, What did the researchers do?, What did the researchers find?, What do the findings mean?” [h] “Ensure that your conclusion/take home message is clear” [h]
Purpose	Reason(s) for writing the summary & what it should convey to the reader.	24 (88.9%)	“Make the research findings presented in the article accessible to those outside the scientific community.” [i] “Help you reach the people who may directly benefit from your research. These are the people who are affected by your discoveries – whose lives have the potential to improve because of your analyses and conclusions.” [i] “A lay summary can be a valuable tool to tell the story of your research. And stories are what we all connect to most. In a lay summary, your research team is the hero, and your passion is the answer to the question of why.” [i] “They make it quick and easy for people outside the research community to understand why your work matters.” [i]
			“Plain language summaries (PLS) communicate the significance of scientific research evidence to a broad audience, including patients and professionals in nearby disciplines, in jargon-free and clear language. As an author, expanding the reach of your work by engaging with a wider audience can help you: • Enable the reader to capture the content quickly and bookmark the paper for in-depth reading. Crucially, PLS improve public engagement with science and medical research. By helping the public to understand biomedical research, researchers can contribute to raising awareness of its value and attracting further public support, engagement, and involvement. • Attract more readers, increasing access to the article and its associated metrics • Connect with patients, caregivers, policy makers, and other decision-makers • Connect with non-specialist healthcare professionals from other fields

			• Improve access to scientific data in a format that is easy to understand • Translate complex science into practical knowledge and initiatives • Expand your professional network and enhance your reputation. Crucially, PLS improve public engagement with science and medical research. By helping the public to understand biomedical research, researchers can contribute to raising awareness of its value and attracting further public support, engagement, and involvement.” [j]
Wording	Specific recommendations regarding wording.	25 (92.6%)	“Should be written in an easy-to-understand manner, using language that is accessible language but does not patronise the reader.” [g] “Sentences should be written in the active voice, rather than the passive voice.” [g]
			“Written in easy-to-understand language rather than complex words (see Universal Patient Language)” [k] “Written in plain English” [k] “Use the active voice rather than the passive voice (for example, “Dr Smith’s team report several improvements” rather than “Several improvements were reported by Dr Smith’s team”).’ [k] “Phrase sentences in neutral language, remaining as objective as possible.” [k] “Use person-centred language rather than focusing on the condition/illness or disability.” [k] “Keep statements factual and avoid providing opinions or speculation on the study’s findings and significance. It is of primary importance that the PLS not be misleading.” [k] “Avoid complex grammatical structures.” [k]
Jargon, Acronyms & Abbreviations	Use of jargon, acronyms or abbreviations.	19 (70.4%)	“Jargon should be avoided other than where necessary; in which case it should be defined in full the first time it is used.“ [l] “Abbreviations should be avoided.” [l]
			“Avoid jargon, use every day English terms to convey your message. If you need to use technical terminology or abbreviations, please explain the term when introduced.” [m]
Resources	Resources for writing a plain language summary from an external source	19 (70.4%)	“For further information on how to write about biomedical and health research in plain English, please read the INVOLVE Plain English Summaries (http://www.invo.org.uk/resource-centre/plain-english-summaries/) resource from the National Institute for Health Research.” [o]
			“A few examples of online resources include the following: https://www.elsevier.com/connect/authors-update/in-a-nutshell-how-to-write-a-lay-summary, https://hbg.cochrane.org/sites/hbg.cochrane.org/files/public/uploads/Writing%20Plain%20Language%20Summaries.docx, https://www.agu.org/Share-and-Advocate/Share/Community/Plain-language-summary” [p]

a. European Urology Oncology; b. Neurology and Therapy; c. European Urology; d. Pain and Therapy; e. Journal of Cardiac Failure; f. Rheumatology and Therapy; g. CNS Drugs; h. Therapeutic advances In Gastroenterology; i. Cancer; j. Expert Review of Respiratory Medicine; k. Expert Review of Gastroenterology & Hepatology; l. American Journal of Clinical Dermatology; m.Therapeutic Advances in Musculoskeletal Disease; n. Cochrane Database of Systematic Reviews; o. Expert Review of Respiratory Medicine; p. Osteoarthritis and Cartilage

Discussion

This is the first study to report a detailed analysis of the author instructions for writing PLSs provided by leading biomedical and health journals. Despite reviewing 534 journals across 10 non-communicable disease areas and 11 journal categories, we found only 27 (5.1%) contained written instructions for PLSs. Author instructions were highly heterogeneous between journals. There was inconsistency regarding the word count (e.g., between 100 and 850 words), structure (e.g., paragraphs or bullet points), and varying levels of detail for other elements in the instructions. Although only one journal recommended consumer involvement in the development of PLSs, many recommended authors consult those who are not experts in their field to review their summary before submission.

Our findings build on and extend existing research in the area. Most previous research on the author instructions for writing PLSs have reported findings for elements such as word count/PLS length, structure or labels for PLSs. Some report findings similar to the current study, however, previous studies have lacked the scope of included health and medical journals and the systematic approach taken with this review. Haughton and Machin (2017), for example, assessed the author instructions for PLSs from the websites of 31 journal publishers, representing ~7630 journals in the fields of biology, economics, medicine, finding word count/length ranged from 75-500 words. Similarly, Shailes' (2017) review of PLSs from biomedical journals and scientific organisations and a small study conducted by Narayanan and colleagues (2018) reviewing 30 journals that contained PLSs both reported PLSs with a wide variance, with the word count/PLS length ranging from one sentence to 1000 words. The results of these studies were like that of our review, which identified a range of 25-30 words to a maximum of 850 words. However, this review significantly extends these findings; word count/PLS length is the only element of PLS author instructions to be reviewed in detail by these previous studies, except for Haughton and Machin (2017), who also recorded the percentage of PLSs that were structured and unstructured

Besides word count, previous research has assessed other elements of PLS writing instructions. Following on from the work of Shailes (2017), FitzGibbon et al. (2020) reviewed a cross-section of 11 journals that produce PLSs from the list compiled and updated by the journal eLife (Shailes, 2017). Contrary to our review, in which most (29.6%) journals did not require PLS, FitzGibbon et al. (2020) found they were mandatory in 8 out of 11 (72.7%). In this way, our study was unique in highlighting the high proportion of journals that consider PLSs optional (70%) in those journals that provide author instructions for PLSs. Haughton and Machin (2017), Shailes (2017) and FitzGibbon et al. (2020) also report labels used by journals for PLSs such as author summary (Duke, 2015; Haughton & Machin, 2017), editor's summary (Haughton & Machin, 2017) key points (Haughton & Machin, 2017), highlights (Shailes, 2017), lay abstracts (Duke, 2015; Shailes 2017) and author summaries (Shailes, 2017). FitzGibbon et al. (2020) note that using varying labels to designate a PLS reduces the chance they will be located by search engines. They suggest the adoption of a universal label such as PLS to increase their accessibility. Although we found fewer labels in our study, this is likely because of our strict inclusion criteria, which meant that the intended audience had to be pre-specified as a non-expert lay public.

While our study evaluated author instructions for writing PLSs, other work has evaluated the content of the summaries themselves. For example, Narayanan (2018) found that 22 out of 30 PLSs from journals contained jargon or technical language. This is a notable finding, as our review showed that most (70.4%) journals provided guidance on avoiding jargon. This suggests that either authors are not following the instructions from journals when writing PLS or journals are not checking PLSs for compliance with their instructions. There is also possible confusion or debate about what is considered jargon, leaving it open to interpretation by authors. Investigation into these factors is an area for future research that could assist in the development of PLS author instructions that are practical and useful.

Consumer involvement is another vital step in developing consistent instructions for writing PLSs identified in this study. Our review found only one (3.7%) journal recommended consumer involvement in the co-design of PLSs, and 11 (40.7%) suggested involvement in reviewing the PLS. There is interest from consumers in PLS co-design, as evidenced by the recent update of the Cochrane guidelines for their systematic reviews. There is also support for PLS co-design from the perspective of researchers, as illustrated by Barnfield et al. (2017), which details the authors' experience working with consumers to develop PLS for some studies in their Cognitive Function after Stroke (COGFAST) project. Authors suggest that “collaboration with members of the public to revise and refine content and layout of lay summaries is more likely to achieve the desired outcome of readability and comprehension.” (Barnfield et al., 2017). Unfortunately, we did not find any data from this review that helps to explain the low proportion of journals recommending consumer involvement in the development of PLSs.

As PLSs become a more common feature of journals, less emphasis could be placed on reinforcing their purpose and value in author instructions. This would allow an increased focus on elements poorly represented or presented with varying levels of detail in some journals at present, such as the type of content to include and recommendations for the use of tools that support plain language and ease of reading, and the involvement of consumers in PLS co-design.

Strengths and limitations

There are both strengths and limitations to this review. The review was limited to journals that specified the audience for the PLS was a non-expert lay public. This excluded many journals that published summaries with labels such as “Highlights” and “Key Points”, most of which did not specify their intended audience. Other reviews of author instructions for writing PLSs took a different approach, including journals for which the intended audience wasn’t explicitly stated as being non-expert. Although our approach limited our review to 27 included journals, we conducted a thorough analysis of the author instructions, reporting in detail on six characteristics of PLSs, such as the label used and consumer involvement, as well as eight elements, such as word count/PLS length, content and structure.

Some journals only provided services or resources for producing PLSs that were outside the scope of our inclusion criteria, so they were not included in the review. For example, some journal publishers, such as Wiley, provide an outsourcing option for PLSs. We did not include these in our study as we couldn’t access the instructions/guidelines writers followed when compiling these PLSs. Had they been included, our data would have been incomplete. Likewise, some journals provided links to additional resources to assist authors, e.g., the plain English summaries resource published by the NIHR (2021). We only included resources produced directly by the journal, not third parties

A final limitation is that several journals were from the same publishing group, and we noted a high level of homogeneity in the PLS author instructions between these journals, e.g., in their purpose and recommendation to avoid jargon. Some slight differences did, however, highlight the value of not assuming journals from the same publishing group have identical author instructions.

Future directions

Given that this review identified that only 5.1% of journals we screened included a PLS, there is a clear and urgent need for the academic publishing industry to include more PLSs in the first instance. There is a lack of understanding of what constitutes a useful PLS, and current instructions are not well supported by evidence (Duke, 2012). As PLSs become a more common part of health research communication, developing consistent guidelines for writing plain language summaries will be necessary. These guidelines should be evidence-based and incorporate feedback from end-users. Since PLS are written according to author instructions provided by journals, such instructions should include guidance to ensure the PLS is written with the audience in mind. To assist this process, end-users involvement is important, and their perspectives on the PLS content, layout and structure should be reflected in any future development of evidence-based PLS instructions. Such consumer involvement is already established as the Cochrane Collaboration and Guidelines International Network (Anne & Rosefield, 2018; Cumpston et al., 2022) both support the participation of consumers in guideline development, and the Cochrane Collaboration recently undertook a revision of their guidelines for writing PLS and incorporated consumer input. The Patient-Centred Outcomes Research Institute and The Cochrane Collaboration recently developed templates for writing PLSs with end-users (Cumpston et al., 2022; Maurer et al., 2021). Future research could build on these templates with a focus on the needs of the end-users of plain language summaries, such as consumers.

Finally, as PLSs become a more common feature of journals, less emphasis may be needed to be placed on reinforcing their purpose and value in author instructions. This would allow an increased focus on elements poorly represented or presented with varying levels of detail in some journals at present such as the type of content to include, and recommendations for the use of a tools that support plain language and ease of reading, and the involvement of consumers in PLS co-design. To make PLSs more accessible to end-users it would be beneficial for journal publishers to consider making them mandatory and also publicly available on searchable databases such as PubMed.

Conclusion

The effectiveness and use of PLSs could be enhanced by developing consistent guidelines that are written with the audience in mind. The guidelines should be created with consumers to help authors write PLSs that best cater to a non-expert lay audience. Existing templates developed with consumers could be further developed and enhanced to cater to other end users of PLSs, such as policymakers and health journalists.

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Availability of data and material: All data was collated from publicly available sources. The datasets generated during and/or analysed during the current study are available from the corresponding author on request.

Ethical approval: not required.

Dissemination to participants and related patient and public communities: A consumer representative reviewed the design and implementation of the study. She also reviewed the manuscript including the plain language summary. Authors plan to disseminate the study findings to the general public through social media, our bi-monthly newsletter and through partnerships with relevant organisations.

Author contributions: Study conceptualisation: Karen Gainey, Danielle Muscat and Kirsten McCaffrey; Methodology: Karen Gainey, Danielle Muscat, Kirsten McCaffrey and Sharon Clifford; Data collection and analysis: Karen Gainey and Jenna Smith; Writing - original draft preparation: Karen Gainey; Writing – reviewing and editing: all authors: Supervision: Danielle Muscat and Kirsten McCaffrey; Project administration: Karen Gainey.

Chapter 3. Are plain language summaries published in health journals written according to instructions and health literacy principles? A systematic environmental scan

This chapter reports an environmental scan, which served as a follow-up study to the scoping review covered in Chapter 2. This study used the same data sources as those used in Chapter 2, with the exclusion of the Cochrane Database of Systematic Reviews, allowing for a more thorough analysis and understanding of how PLSs are regarded by the included journals.

This study aimed to determine (i) the degree of compliance of published PLSs against the PLS author instructions in health journals and (ii) the extent to which PLSs meet health literacy principles such as readability.

As noted elsewhere, other authors have reported on aspects of the author instructions for writing PLSs; however, none had compared these instructions to PLSs from the same journals to determine the level of compliance. I undertook this study because it posed an opportunity to explore a research gap and pose research questions as yet unanswered.

Similarly to the previous study in Chapter 2, the data for this study comprised grey literature obtained from journal websites. My supervisors and I determined that an environmental scan would be the most suitable methodology. Based on a thorough review of guidance on the EQUATOR network, there were no corresponding guidelines for environment scans, so no reporting guidelines were completed for this study.

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Abstract

Background: Plain language summaries (PLSs) are easy-to-understand summaries of research articles that should follow plain language and health literacy principles. PLS author instructions from health journals are intended to help guide authors on word count, structure, and the use of jargon within PLSs. However, it is unclear whether published PLSs currently adhere to author instructions.

Objectives: This study aims to determine (a) the degree of compliance of published PLSs against the PLS author instructions in health journals and (b) the extent to which PLSs meet health literacy principles.

Study design: We conducted a three-part systematic environmental scan**.**

Methods: We examined 26 health journals identified from a previous review. In part one, we assessed the inclusion frequency of PLSs in the 26 journals. In part two, we evaluated the level of compliance of PLSs to PLS author instructions. In part three, we conducted a health literacy assessment of the PLSs, measuring grade reading level and percentage of complex words using the SHeLL Health Literacy Editor.

Results: We found PLSs for 20/26 (76.9%) included journals. In our assessment of the level of compliance of PLSs to PLS author instructions, we found that no journal achieved 100% compliance with PLS author instructions. The highest level of compliance was 86%, and the lowest was 0%. The mean reading level of included PLSs was grade 15.8 (range 10.2 to 21.2and the mean percentage of complex words 31% (range 8.5-49.8%).

Discussion: PLS are an important way consumers can access research findings. We found a lack of compliance between PLS author instructions and PLSs published in health journals that may impede access and use by consumers. This study highlights the need for better ways to support authors in adhering to PLS instructions and improved monitoring by journals.

Article summary

Strengths and limitations of this study

- This study is the first to provide the compliance of PLSs with journal author instructions for writing PLSs.
- We provide a health literacy assessment (reading level and use of complex words) of PLSs from journals covering a range of medical specialities.
- Our dataset only included journals that published PLSs in English, so it’s unclear if the inclusion of PLSs published in languages other than English might have altered the results.
- Author instructions for writing PLSs were inconsistent in terms of the elements included and the amount of detail provided, so direct comparisons were not straightforward.

Plain language summary

- Plain language summaries (PLSs) are a good way of getting health research to a general audience.
- Authors need to follow a guide from journals for writing a PLS i.e., how long it should be and what it should include.
- We compared 53 PLSs from 20 journals to see how closely they followed these guides and whether they were useful for a general audience e.g. written at a reading level of grade 8 or lower.
- Most PLSs were not based on the journal guides, and most were written at much higher reading levels than grade 8.
- It might be time to rethink how we write PLSs to make sure they best suit those who read them.

This plain language summary was co-developed with a consumer representative that also consulted on the corresponding study. It was used to promote the study on social media e.g., Twitter (X), Blue Sky and LinkedIn.

Introduction

Over the past two decades, the availability of health information in all forms has increased, most notably that of online information (Jacobs et al., 2017). This increased access has led to concerns about the quality and trustworthiness of online health information and whether it is suitable for a general audience (Jacobs et al., 2017). Plain language summaries (PLSs) are important for providing consumers with reliable health research results. PLSs are easy-to-understand summaries of research articles that follow principles of plain language and health literacy, such as avoiding or explaining jargon (Cheng & Dunn, 2015; NIHR, 2021). PLSs can play a vital role in helping to prevent the spread of health misinformation, the impact of which was highlighted by the recent pandemic (James & Beeby, 2022). This is particularly important as patients and practitioners often use online health information to guide medical decisions or share it with others, e.g., through peer networks such as online patient groups (Ramsay et al., 2017). By providing health information to the public in a way they can understand and use, PLSs can help improve health literacy (Cheng & Dunn, 2015).

Although agencies differ in their specific readability recommendations, most agree that written material for a general audience should be written at a reading level no higher than grade 8 (Ayre et al., 2023; Cheng & Dunn, 2015; Daraz et al., 2018; South Australia Health, 2021). Unfortunately, readability analyses of PLSs in health journals consistently show the reading level of PLSs is consistently higher than grade 8 (Carvalho et al., 2019; Wen et al., 2023; Yi & Yang, 2023).

It Is standard practice for health journals to provide instructions to guide authors as they prepare and submit their manuscripts, referred to as author instructions or guidelines for authors. Journals that publish PLSs include important details for the PLS in these author instructions, covering word limit, content, structure and the use of jargon, acronyms, and abbreviations. Instructions related to PLS word limit and structure may vary between journals based on formatting requirements. Those instructions relating to content help to ensure the information in the PLS is based on the article and valuable to the reader. In principle, instructions associated with the use of jargon, acronyms, abbreviations and reading level can assist with the readability of the PLS and suitability for the intended audience. However, our recent scoping review identified that while most (70%) journals that publish PLSs had author instructions that included advice about the use of jargon, only one journal included recommended the PLS authors use a readability tool (Gainey et al., 2023). Our review also identified a high degree of variability in author instructions for writing PLSs across journals (Gainey et al., 2023).

In academic publishing, author instructions for PLSs help guide authors to know what a journal wants to be included in a PLS and how it should be structured. There is, however, little value in a journal, including author instructions for writing PLSs if they are not reflected in the journal's published PLSs. The level of compliance between PLSs and their corresponding author instructions in health journals has not been investigated; however, similar research was conducted by Malicki et al. on general author instructions (i.e., those for the entire manuscript). Specifically, Malicki and colleagues conducted a systematic review and meta-analysis of 153 studies that analysed author instructions (Malicki et al., 2021). Twelve of these studies analysed adherence of published articles to the author instructions from the journal, with most (83.3%) achieving suboptimal adherence (<80% of manuscripts adhered to the author instructions or partially or completely). However, the extent to which PLSs reflect the author instructions on which they are based is unknown. Although the studies in Malicki and colleagues' review (2021) did not measure adherence to PLS author instructions explicitly, their results suggest that instructions for PLSs may not be followed in many instances.

The purpose of this study Is to determine (a) how frequently PLSs are included with original research articles in journals for which PLSs are permitted, (b) the degree of compliance of published PLSs against the PLS author instructions in health journals and (c) the extent to which PLSs meet health literacy principles such as readability.

Methods

Inclusion criteria and selection of health journals

Our previous scoping review identified health journals included in this environmental scan (Gainey et al., 2023). This scoping review included a comprehensive search of 534 health journals covering 11 journal categories linked to the top 10 non-communicable diseases (Gainey et al., 2023). In our original review, we located author instructions from 27 journals that met our inclusion criteria, which were that the journal (i) published text-based PLSs (as defined by the INVOLVE PLS resource published by the National Institute for Health Research (NIHR) (NIHR, 2021) (ii) included author instructions indicating the audience for the PLS was consumers and (iii) published PLSs in English (Gainey et al, 2023). For this study, we excluded one journal from this scoping review (Cochrane Database of Systematic Reviews published by Wiley) because it exclusively publishes systematic reviews, and the focus of this study was journals that published original research articles.

The 26 included journals were Postgraduate Medicine; JACC-Cardiovascular Imaging; Journal Of Cardiac Failure; European Urology Oncology; Cancer; Osteoarthritis And Cartilage; Therapeutic Advances In Musculoskeletal Disease; Rheumatology And Therapy; Journal Of Applied Sport Psychology; European Urology; European Urology Open Science; European Urology Focus; Journal Of Asthma And Allergy; Expert Review Of Respiratory Medicine; Neurology And Therapy; CNS Drugs; Pain And Therapy; Journal Of Hepatology; Gastroenterology; Therapeutic Advances In Gastroenterology; Expert Review Of Gastroenterology & Hepatology; Ophthalmology And Therapy; British Journal Of Dermatology; American Journal Of Clinical Dermatology; Dermatology And Therapy and Clinical Cosmetic And Investigational Dermatology.

Most of these journals (73%) did not require a PLS for all published articles, i.e., the PLS was optional (Gainey et al., 2023).

Data collection and analysis

This study was divided into three sections, outlined in Figure 1. Two reviewers (KG & JS) independently assessed compliance for the PLSs from each journal. Any discrepancies were resolved through discussion until 100% consensus was achieved, involving a third person as needed (DM).

Part one – Assessing the inclusion of a PLS in original research articles

Part one aimed to determine the extent to which the included journals published PLSs with original research articles. Our strategy was to search a maximum of 20 original research articles per journal to locate three articles with an accompanying PLS. Two reviewers searched journals in

September and October 2022, beginning with the most recently published volumes and working chronologically from the publication date. Reviewers recorded the number of articles searched to locate three with a corresponding PLS. For example, if reviewers located three PLSs after searching 14 articles, the search was stopped at this point. Reviewers accessed journal articles through the library subscriptions held by The University of Sydney, Australia.

Part two – Comparing identified PLSs with PLS author instructions

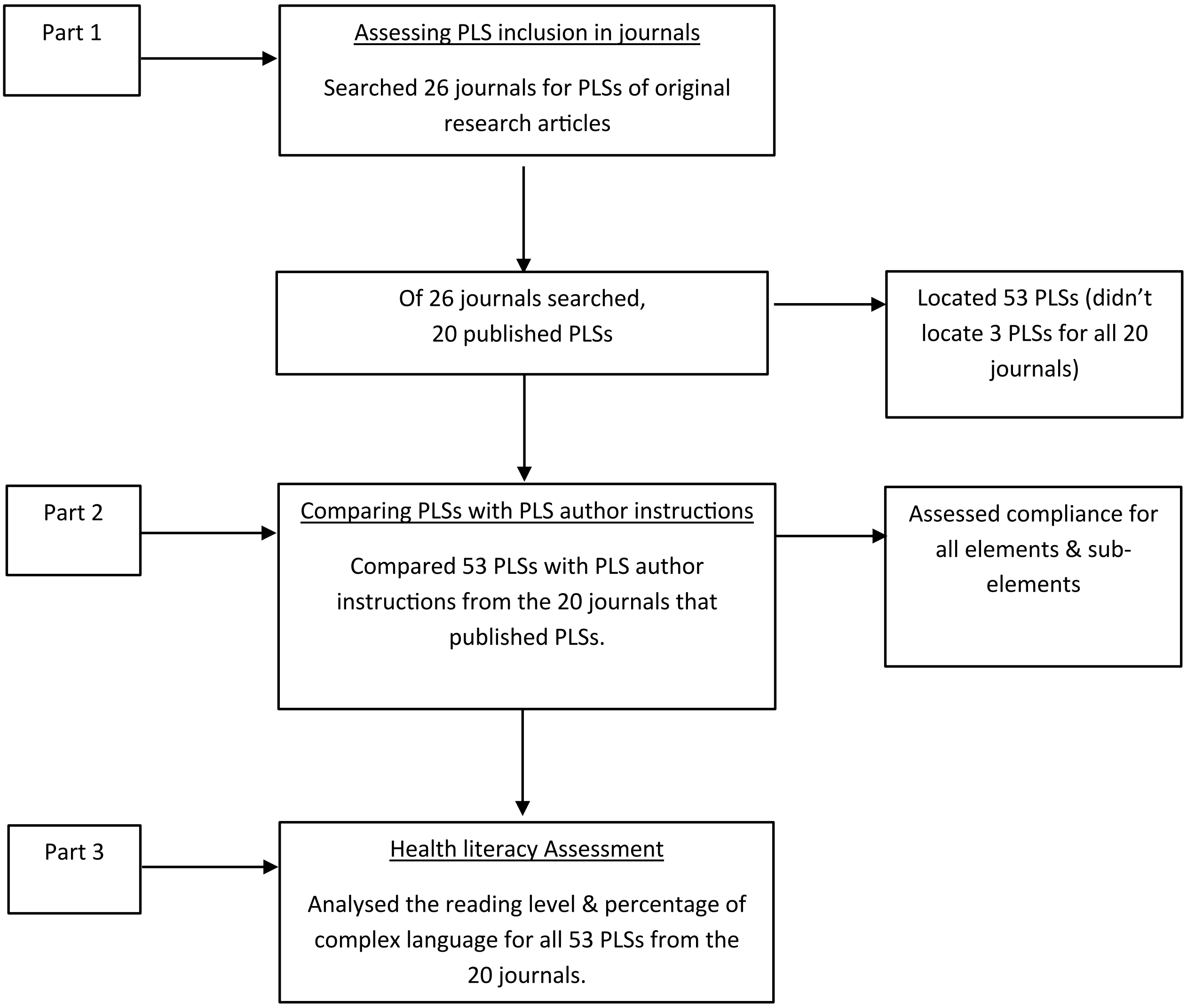
For part two, we compared PLSs with author instructions to determine the level of compliance. Using the PLSs we identified in part one, we compared each PLS with the corresponding PLS author instructions provided by the publishing journal. We assessed the level of compliance across those elements from Gainey et al. (2023), for which a compliance review was feasible. These were word count/PLS length, content, structure, wording, and the use of jargon, acronyms, and abbreviations. We defined feasibility based on the elements from Gainey et al. (2023) that we could easily measure using existing tools or a priori consensus. Therefore, we excluded the elements of purpose and resources as we considered text relating to the purpose of the PLS as informational rather than instructional. We could not determine whether the PLS author has used any of the included resources when writing the PLS.

We broke each of the elements into sub-elements to simplify the assessment process. Two independent raters (KG and JS) referred to the journal's author instructions to assess each sub-element. They determined the extent to which each published PLS was consistent with them, using a three-point rating scale of "full", "partial", or "non" compliance. We calculated overall compliance as a percentage across all PLSs for each journal. Compliance of 80% was considered "high", 51-79% was "medium" compliance, 31-50% was "low" compliance and ≤30% was "very low" compliance.

Assessing some of these elements is subjective, so *a priori* criteria were established and iteratively refined by reviewers during data collection. When determining the use of jargon, we utilised a validated tool, 'The De-Jargonizer' (Rakedzon et al., 2017). Raters (KG and JS) copied PLS text into the tool and recorded the percentage of 'rare' words.

Appendix B (i) shows the method or criteria used to assess compliance, compliance scoring and an example of the elements and sub-elements from the author instructions.

Figure 1. Data collection and analysis process



Part three – Health literacy assessment

The purpose of part three was to assess the suitability of the PLSs for a consumer audience, using health literacy principles such as readability and the use of complex language. To do this, we used an online real-time editor (i.e., the SHeLL Editor) (Ayre, et al., 2023) for both analyses. The SHeLL editor (Ayre, et al., 2023) measures readability using the Simple Measure of Gobbledygook (SMOG) Index. Complex language is determined by the SHeLL Editor based on the frequency of uncommon words, defined based on the New General Service List; a database of more than 270 million words from various English-language sources. In our assessments, we copied the text from each PLS into the Editor and recorded the grade reading level and percentage of complex language (with higher scores indicating greater text complexity).

Anderson and colleagues (2021) noted that readability scores are impacted by jargon or complex words that are unavoidable as their use can be important to the understanding of the subject matter in the PLS. Using this rationale, we excluded some jargon or complex words from our readability analysis where use of these words was considered appropriate, conveyed important detail or context to the reader or where there was no plain language equivalent. Specifically, when preparing the text from each PLS for the readability and complex language analysis, we excluded words from the following categories:

* Term for an illness or disease if this term is the subject of the PLS e.g., we would remove the term "psoriasis" from the PLS of a paper titled "Treatment Patterns for Targeted Therapies, Nontargeted Therapies, and Drug Holidays in Patients with Psoriasis".

* Medication / pharmaceutical product e.g., Vericiguat. This did not apply to descriptive terms such as antibiotic or anti-inflammatory.

* Medical device or other commercial product e.g., HeartLogic

* Company name e.g., Neurolief Ltd

* Study or trial name e.g., SPARTAN study

* Geographical location e.g., Spain

* Population descriptor e.g., indigenous

After we obtained scores for readability and complex words for all PLSs, we applied a rating scale of "excellent", "good" and "poor". Written material aimed at the public should have a reading level of grade 8 or lower so a rating of excellent was given to PLSs with a reading level was ≤ grade 8 (Ayre, et al., 2023; Cheng & Dunn, 2015; Daraz, et al., 2018; South Australia Health, 2021). A "good" rating was given if the reading level was > 8, 9 or 10, and a "poor" rating was given if the reading level was >10. For complex words, a rating of "excellent" was given if the complex language score was ≤ 5%, "good" if it was 5-10% and "poor" if it was > 10%. In the absence of comparative literature, reviewers determined these rating through a priori consensus.

Patient and public involvement

We consulted two consumer representatives (SL and SC), who were engaged as part of the research team, to provide input on the study. SL reviewed the study methods and SC provided ongoing feedback on the study methods and results, offering insight from the perspective of an end-user of PLSs. SC also reviewed the full manuscript and co-wrote the PLS for this study.

Results

Part one – Assessing the inclusion of a PLS in original research articles

We found PLSs for 20 of the 26 (76.9%) included journals, locating a total of 53 PLSs. For 15/26 (57.7%) journals we located three PLSs, for 3/26 (11.5%) journals we located two PLSs, in 2/26 (7.7%) journals we located one PLS and in 6/26 (23.1%) journals we located zero PLSs. Of the seven journals for which PLSs were stated as being mandatory, we found PLSs in six.

For half of the journals (14/26, 53.8%), we had to search the maximum of 20 articles to locate three with a PLS. Alternatively, for seven journals, we only had to search the minimum (i.e., three articles) to locate three with a PLS. See Table 1 for results from part one of the study i.e., the number of PLSs located for each journal.

Table 1. Number of plain language summaries located in each journal

Journal Name	Total number PLSs found	Total number articles searched to locate ≤ 3 PLSs
American Journal Of Clinical Dermatology	3	10
British Journal Of Dermatology	3	3
Cancer	3	5
CNS Drugs	3	7
Dermatology And Therapy	3	19
European Urology	3	3
European Urology Focus	3	3
European Urology Oncology	3	3
European Urology Open Science	3	3
Journal Of Applied Sport Psychology	3	3
Journal Of Asthma And Allergy	3	20
Journal Of Cardiac Failure	3	6
Journal Of Hepatology	3	3
Rheumatology And Therapy	3	20
Therapeutic Advances In Gastroenterology	3	10
Expert Review Of Respiratory Medicine	2	20
Neurology And Therapy	2	20
Pain And Therapy	2	20
Clinical Cosmetic And Investigational Dermatology	1	20
Ophthalmology And Therapy	1	20
Expert Review Of Gastroenterology & Hepatology	0	Did not locate any PLSs
Gastroenterology	0	Did not locate any PLSs
JACC-Cardiovascular Imaging	0	Did not locate any PLSs
Osteoarthritis And Cartilage	0	Did not locate any PLSs
Postgraduate Medicine	0	Did not locate any PLSs
Therapeutic Advances In Musculoskeletal Disease	0	Did not locate any PLSs
Total	53	238

Part two – Comparing identified PLSs with PLS author instructions

The results for part two of the study are presented in Tables 2 and 3. Out of the 20 journals assessed, no journal achieved 100% compliance with all author instructions. The highest level of compliance was 86% (i.e. high compliance) and the lowest was 0% (i.e. very low compliance). One (5%) achieved a compliance rating of high (i.e. ≥ 80% compliance) and fourteen (70%) achieved a rating of medium (i.e. 51-79% compliance). The compliance for five (25%) journals was rated as low or very low (i.e. ≤ 50% compliance). Four of the journals with low or very low compliance were from the same journal publisher and contained five or fewer sub-elements in their PLS instructions. Two of these achieved zero compliance.

The degree of compliance varied between author instruction elements and sub-elements. Since author instructions vary between journals, not all sub-elements are included in the instructions for all journals i.e., although we analysed 53 PLSs, results for some sub-elements are less than 53.

No element or sub-element achieved 100% compliance; however, four sub-elements achieved a high compliance rating. These were the word count/PLS length sub element of “maximum number of words”, the content sub-elements “based on the manuscript” and “main findings/take-home message”, and “impact/”so what” of research” and the jargon, acronym and abbreviations sub-element “abbreviations – explain or avoid”. Of the eighteen sub-elements, more than half 11/18, 61.1%) were given a low or very low compliance rating. This means most PLSs were not written in accordance with these aspects of the author instructions. For the structure sub-element of “paragraph style of similar”, approximately one third fully complied (27.3%), one third partially complied (38.6%) and one third did not comply (34.1%). Only 11 (35.5%) PLSs fully complied with the instruction to explain or avoid jargon, with 11 (35.5.%) failing to comply. Jargon scores ranged from 0% to 18%, with a mean and median of 5%.

Table 2. Compliance for all journals

Journal	Number sub-elements	Number PLSs located	Compliance score for each PLS			Compliance score all PLSs	Compliance score all PLSs (%)	Compliance rating *
			PLS 1	PLS 2	PLS 3			
American Journal Of Clinical Dermatology	7	3	13	12	12	37	88	High
Rheumatology And Therapy	7	3	10	13	13	36	86	High
British Journal Of Dermatology	9	3	15	13	14	42	78	Medium
Neurology And Therapy	7	2	10	11	0	21	75	Medium
Expert Review Of Respiratory Medicine	13	2	19	19	0	38	73	Medium
Journal Of Asthma And Allergy	12	3	17	16	19	52	72	Medium
Pain And Therapy	7	2	8	12	0	20	71	Medium
Journal Of Applied Sport Psychology	13	3	18	18	18	54	69	Medium
Clinical Cosmetic And Investigational Dermatology	13	1	18	0	0	18	69	Medium
European Urology Oncology	4	3	6	4	6	16	67	Medium
CNS Drugs	7	3	9	10	8	27	64	Medium
Therapeutic Advances In Gastroenterology	15	3	18	19	16	53	59	Medium
Dermatology And Therapy	8	3	10	10	7	27	56	Medium
Journal Of Cardiac Failure	3	3	4	3	3	10	56	Medium
Cancer	10	3	9	10	12	31	52	Medium
Ophthalmology And Therapy	9	1	8	0	0	8	44	Low
Journal Of Hepatology	5	3	2	7	3	12	40	Low

European Urology	4	3	2	2	0	4	17	Very low
European Urology Focus	4	3	0	0	0	0	0	Very low
European Urology Open Science	4	3	0	0	0	0	0	Very low

- High = ≥80%, Medium = 51-79%, Low = 50-31%, Very low = ≤30%

Table 3. Compliance for all elements and sub-elements of PLSs

Element	Sub-element	Frequency in author instructions (N=53)	Compliance score all PLSs	Percentage compliance (%)	Compliance rating *
Word count/PLS length	Maximum number of words	38	70	92.1	High
	PLS Length	15	10	50.0	Low
Content	Based on manuscript	24	46	95.8	High
	Background	17	26	76.5	Medium
	Methods	15	25	83.3	High
	Main findings/take-home message	29	35	60.0	Medium
	Impact/"so what" of research	18	23	63.9	Medium
	Other	3	1	16.7	Very low
Structure	Bullet points	10	8	40.0	Low
	Paragraph style or similar	48	68	70.1	Medium
	Other	3	3	50.0	Low
Wording/language	Plain English/easy to understand	43	31	36.0	Low
	Active voice	29	25	43.1	Low
	First person	3	0	0	Very low
	Person-centred language	9	14	77.8	Medium
	Reading level/Readability	2	4	50.0	Low
	Other	18	18	50.0	Low
Jargon, Acronyms & Abbreviations	Jargon – explain or avoid	32	31	48.4	Low
	Abbreviations – explain or avoid	29	56	96.6	High

- * High = ≥80%, Medium = 51-79%, Low = 50-31%, Very low = ≤30%

Part three – Health literacy assessment

Based on the health literacy assessment, no PLS was likely to be suitable for a general audience, i.e. no PLS met the standard reading level of grade 8 recommended for written material aimed at a general patient audience (Ayre, et al., 2023; Cheng & Dunn, 2015). Using the edited scores for readability (with words excluded) the lowest reading level was grade 10.2 and the highest was 21.2-. The mean readability score was a grade reading level of 15.8 and the median was 15.9. All PLSs were rated as "poor", meaning they had a reading level of > grade 10. Using the edited scores for the complex language analysis (with words excluded) the range was from 8.5% to 49.8%. The mean was 31.0% and the median was 31.7%. All but one PLS was rated as "poor", meaning 52/53 (98.1%) had a >10% complex words.

In Appendix B (ii) we show results of the health literacy assessment. We included both raw and edited scores for both analyses. The raw scores are those prior to excluding any words and the edited scores are after excluding words.

Discussion

We conducted a systematic environmental scan to determine (a) how frequently PLSs are included with original research articles in journals for which PLSs are permitted; (b) the degree of compliance of published PLSs against the PLS author instructions in health journals and (c) the extent to which PLSs meet health literacy principles such as readability. We found 53 PLSs across 20 journals. When assessing PLS compliance to journal instructions, only two journals were rated as highly compliant, while two thirds (65%) of journals obtained a medium level of compliance and five were given either a low or very low compliance rating. Compliance ratings for sub-elements of PLSs varied greatly but was highest for elements such as word count/PLS length and lowest for elements such as wording. No PLS met the reading level of grade 8 recommended for written material aimed at a general patient audience (Ayre, et al., 2023; Cheng & Dunn, 2015), and across PLSs, an average of 31% percent of words were considered complex. There was a high level of homogeneity between the PLS author instructions from journals from the same publisher, which had an impact on the results. This is particularly the case for the journals that received low and very low compliance rating.

The poor compliance for some journals and sub-elements identified in this study could be caused by many factors. As PLSs are not mandatory for most biomedical journals, authors unfamiliar with writing PLSs may not consider including a PLS with their manuscript submission. Also, some researchers may not prioritise PLSs or find them too consuming to produce due to a lack of experience communicating their research with a general audience (Brownell et al., 2013). In this instance, authors may not consult PLS author instructions or only refer to some sub-elements such as word count and structure which are easiest to follow. This may be exacerbated by journal editors if they do not reinforce the author instructions when manuscripts are accepted for publication, regardless of whether the PLS is optional or mandatory. This could be due to a lack of time, resources, and commitment to ensuring the PLS is useful for the intended audience, or an assumption that the author has followed the author instructions. There are generally no specific criteria for peer reviewers in relation to reviewing PLSs; however, these assumptions are yet to be investigated in an empirical research study.

A lack of detail and consistency in PLS author instructions may also be a factor in low compliance. Nambiar and colleagues (2014) assessed 20 sub-categories in author instructions from 80 journals (40 biomedical and 40 physical science) (Nambour et al., 2014). They found no journal had a perfect score for completeness and clarity. Many journals had incomplete information for word limits and intended audience (Silvagnoli et al., 2022). Applied to PLSs specifically, unclear and incomplete author instructions, particularly regarding intended audience, can lead to a PLS written at an inappropriate reading level, unsuitable for a lay non-expert audience. This problem is worsened when limited detail is provided for the use of jargon, acronyms and abbreviations, and complex language.

Our findings pertaining to the high grade reading level of PLSs mirror the findings of other studies (e.g., Carvalho et al., 2019; Wen et al., 2023; Yi & Yang, 2023). The PLSs in this study ranged from grade 10 to grade 21, much higher than grade 8, which is recommended for a general audience (Ayre et al., 2023; Cheng & Dunn, 2015; Daraz et al., 2018; South Australia Health, 2021). The main purpose of PLSs is to convey health research to a general audience. If a PLS is unable to be easily understood by a general audience, not only is effort wasted in producing it, but there is the potential for the message of the study to be misunderstood by the reader. PLSs that contain jargon or complex wording could be difficult for a general audience to understand fully. If the take-away message of PLS is misunderstood, it could increase the potential for incorrect health information to be used to inform medical decisions. This incorrect message may then be shared on social networks, e.g., patient support groups or through peer networks, worsening the spread of misinformation (Chen & Wang, 2021).

We have already discussed potential reasons for non-compliance with PLS author instructions such as a lack of experience writing for a general audience. These reasons may also apply to our findings for health literacy principles i.e., the mean and median reading levels were approximately grade 16, almost all PLSs contained high percentages of complex language and only half of the PLSs complied with the instruction to avoid jargon. Other factors should also be considered, and they relate to the type of people who read PLSs. Research about the health literacy level of people who access PLSs is limited. What is known, suggests that people who read PLSs have a higher health literacy level than the general public and display high health information seeking behaviour (Maurer et al., 2021). Silvagnoli and colleagues (2022) found that participants preferred PLSs written at a grade 9-11 reading level, finding PLSs at this reading level contained enough detail to convey the message of the PLS without oversimplifying the language used. The Patient-Centered Outcomes Research Institute (PCORI) also acknowledge that jargon may be appropriate to include in some PLSs even though it will likely increase the reading level (Maurer et al., 2021). What matters most is ensuring any jargon used is relevant and defined when first used (Stoll et al., 2022). Perhaps it is time to reconsider the reading level we recommend for PLSs to accommodate the appropriate use of complex words and jargon. A reading level of grade 8 may be too restrictive and compromise the message of the PLS.

Strengths and limitations

This is the first study to assess the level of compliance between PLSs in health journals and the PLS author instructions on which they are to be based. Although there was a degree of subjectivity in rating some sub-elements, we used a systematic approach including two independent raters to conduct the journal search and data analysis using a priori criterion to reduce bias. Also, we used gold standard readability formulas and validated tools for assessing reading level and jargon (SHeLL editor (Ayres et al., 2023) and the De-Jargonizer tool (Rakedzon et al., 2017).

It is unclear what role, if any, language may play in compliance between author instructions and PLSs. For example, some journals use the terminology “author instructions” whereas others use “author guidelines”, “submission guidelines” or “guide for authors”. Unfortunately, our dataset was not large enough to segment results according to these terms. The scope of this study was limited to assessing grade compliance only, so we are not able to comment on the appropriateness or usefulness of any elements within the PLS author instructions themselves.

Future directions

Support from journals to make PLS instructions easier to follow might improve compliance. The Golden Rules for scholarly journal editors were published in 2014 by the European Association of Science Editors (EASE) and they suggest that author instructions should be “simple and easily understood” (Ufnalska & Terry, 2020). They also suggest a table at the beginning of a journal’s author instructions that outlines the important information needed for the manuscript submission (Ufnalska & Terry, 2020). This proposed table would cover areas such as word limits, title page information, structure, formatting, author forms required, submission notes such as tables, figures and supplementary files, and journal policies (Ufnalska & Terry, 2020). Resources such as this table could provide authors with a more standardised guide during their article preparation and submission (Ufnalska & Terry, 2020). One limitation of this table is that it does not include PLSs (Ufnalska & Terry, 2020). If this table or similar resources are to be adopted by journal publishers, it is vital that PLSs are included, whether they are optional or mandatory. Monitoring systems to assess the level of compliance between PLSs of submitted articles and the journal's instructions for writing PLSs could be initiated by health journals prior to manuscript approval.

Conclusion

The PLSs from most of the journals we included in our study were rated as having a medium level of compliance with the author instructions. There was wide variation in the degree of compliance with elements and sub-elements, which could be due to how easily authors are able to comply with each journal's PLS author instructions. Several international groups across various industries are collaborating to develop evidence-based guidelines for PLSs (Rosenberg, 2022). This is an opportunity for experts in this field to challenge current assumptions about PLSs and produce guidelines that are contemporary as well as practical. Journals could assist by ensuring PLS instructions are easy to follow, and through monitoring compliance. More data on the users of PLSs would provide a fuller understanding of how to address this issue.

Statements

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Research ethics and consent

None required.

Competing interests

The SHeLL Health Literacy Editor is a research tool owned by the University of Sydney. It is sublicensed to Health Literacy Solutions PTY Ltd to enable wider public use. DMM and KM are co-directors of Health Literacy Solutions PTY Ltd. DMM and KM take no personal income from Health Literacy Solutions PTY or the Health Literacy Editor.

Author statement

Karen M. Gainey, Jenna Smith, Kirsten J. McCaffery, Sharon Clifford, and Danielle M. Muscat have completed the International Committee of Medical Journal Editors (ICMJE) uniform disclosure form at http://www.icmje.org/coi_disclosure.pdf and declare no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous 3 years; and no other relationships or activities that could appear to have influenced the submitted work, with the exception of Health Literacy Solutions Pty Ltd, at which Kirsten McCaffrey and Danielle Muscat are directors.

Data availability statement

All data were collated from publicly available sources. The datasets generated and/or analysed during the current study are available from the corresponding author upon reasonable request.

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language summaries of published health research articles: how well are we doing?. Abstracts accepted for the 27th Cochrane Colloquium, London, UK. Cochrane Database of Systematic Reviews 2023; (1 Supp 1). https://doi.org/10.1002/14651858.CD202301

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Chapter 4. Perspectives of people with chronic illness about plain language summaries: A qualitative analysis

This chapter reports a qualitative study with users of PLSs, all with chronic health conditions. This study aimed to investigate the health information-seeking behaviour of people with chronic health conditions and what they see as important in PLSs in terms of content, design and structure, and the labels used.

As noted in the Introduction, the perspectives of people familiar with PLSs remain largely unexplored. Of the studies conducted, none have explicitly focused on people with chronic illness. I chose this group for two reasons. First, the literature indicates that they are high users of health information, including journal articles. Second, chronic illnesses align with the top 10 non-communicable diseases, which served as a context for the studies in Chapters 2 and 3.

To ensure reporting transparency, I used a tool developed by Braun and Clarke and published as Table 1 in their 2020 paper "One size fits all? What counts as quality practice in (reflexive) thematic analysis?". This checklist is included in this thesis as Appendix C (iv).

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Abstract

Background: People with chronic health conditions tend to look for information from various sources. Although information online is accessible, the quality varies, and articles in scientific journals are not written for a general audience. Given this, plain language summaries (PLSs) may be a helpful source of information, especially for people with chronic medical conditions. PLSs contain reliable information that is written in plain, easy-to-understand language.

Objectives: We investigated the health information-seeking behaviour of consumers with chronic health conditions, seeking to understand what they see as important in a PLS concerning content, design and structure, and the labels used.

Methods: We conducted semi-structured focus groups and interviews with 19 participants from 6 countries, all with a chronic medical condition. Qualitative data was analysed using reflexive thematic analysis.

Results: We developed four themes: (1) 'Accessing information in a competitive landscape of health information'; (2) 'I really don't see the patient in this at all'; (3) 'Co-design should be meaningful, not tokenistic' and (4) 'A way forward: Approach PLSs with creativity'. Participants highlighted the importance of PLS labels, the need for actionable content, and the recommendation to vary the reading level depending on audience needs.

Conclusions: The results of this study suggest that PLSs produced with consumer input could elicit PLSs that better meet audience needs, focusing on information that is actionable, accessible and written with useful content that is detailed but still respectful of the reader. Consequently, PLSs could become a more helpful source of reliable information, particularly for people with chronic health conditions.

Contribution to health promotion

- Plain language summaries (PLSs) can be a useful way of getting reliable health information, especially about chronic medical conditions.
- People with chronic medical conditions have diverse needs and PLSs could be improved to better meet these needs, e.g., with content they could action.
- Participants suggested that some level of medical jargon could be included in PLSs and the reading level could be higher than the recommended Grade 8.
- Publishers of health journals could improve the usefulness of PLSs by considering creative ways of providing PLSs and ensuring readers are involved in their design.

Plain language summary

- We talked to 19 people from six countries about their thoughts and experiences with plain language summaries (PLSs).
- Most participants were women, aged 60-69, had a university level education, lived in Australia, and had read a PLS in the month prior to the study.
- We found that people wanted PLSs that contained practical information that they could easily use to help with their treatment decisions.
- It was also important that PLSs were accessible and written using language that respects the reader.
- Co-design was seen as important but only if done in a meaningful, not tokenistic way. People wanted their contribution to be valued.
- Some medical conditions had an impact on the way information is processed. More choice of formats could be a useful way of reaching more people. Ideas included podcasts, video summaries, infographics or a mixture.
- Participants suggested that some level of medical jargon could be included in PLSs.
- The reading level could be higher than the recommended grade 8.
- Journal publishers should focus more on who is reading PLSs. Journals could use creative ways to develop PLSs that better suit their audience.

Introduction

Non-communicable diseases (NCDs) or chronic health conditions are responsible for 74% of the global burden of disease (Osbourne et al., 2022). Members of the public with chronic health conditions commonly look beyond their treating medical practitioner for health information, particularly the internet and social media (Jia et al., 2021), but also scientific journals (Higgins et al., 2011; Pushparajah et al., 2018). Although information online is accessible, the quality varies (Kuehn, 2017), and articles in health and medical journals are not written for a general audience (Goldstein & Krukowsi, 2023). An alternative source of information is plain language summaries (PLSs). They are summaries of research articles written in plain, easy-to-understand language aimed at a non-scientific audience (Kirkpatrick et al., 2017). PLSs are primarily found in journals but are also produced by consumer groups and government agencies. By spanning the gap between general health information and scientific research, PLSs are well-placed to offer readers a trustworthy source of information, making them a potentially important means of communicating health research to the public (Pushparajah et al., 2018).

There has been some research exploring aspects of PLSs including, for example, literature examining the content of health and medical journals' author guidelines for PLSs (Gainey et al., 2023; Haughton & Machin, 2017; Stoll et al., 2022) as well as the readability of published PLSs (Anderson et al., 2021; Carvalho et al., 2019; Silvagnoli et al., 2022). The latter studies have consistently shown that PLSs are written at reading levels above the level of Grade 8 that, is recommended for a general audience and equates to an education level of middle school or high school, depending on the country (Readable, n.d.). This finding is supported by our recent study (Gainey et al., 2024) that found the grade reading level of PLSs ranged from Grade 10 to Grade 21, equating to education levels from high school to post-graduate (Readable, n.d.). Less attention, however, has been dedicated to exploring consumer perspectives of this information source (Glenton et al., 2010; Kirkpatrick et al., 2017; Santesso, 2015).

Of the research that has been done, some studies have focused on the importance of including consumers in the development of PLSs, including detailed steps to take in the co-design process (Barnfield et al., 2017; Wada et al., 2020). However, a literature search yielded no research or examination of consumer involvement in the initial development of PLSs in academic publishing. When PLSs became a distinct part of scholarly publishing in the late 1990s (Haughton & Machin 2017), it is likely their inclusion was made on the assumption by journal editors they would be a valuable addition to research papers for consumers and researchers unfamiliar with the research topic. Although many studies have since reported feedback from consumers on PLSs (e.g., Glenton et al., 2010; Nunn & Pinnfield, 2014; Santesso et al., 2015), there is no published data to suggest that consumers were consulted on whether they thought PLSs would be helpful and something they would use before they were implemented. Nor were they consulted at that time about the design, content, layout, and the name or label given to PLSs.

This project investigated the health information-seeking behaviour of consumers with chronic health conditions and what they see as important in PLSs published in health and medical journals regarding content, design and structure, and the labels used.

Methodology

Definition of terms

We understand that there is no universally agreed-upon term for members of the community who have a special interest in health research, either through strong health information-seeking behaviours or through involvement in the research process. For this study, we use the terms consumer, patient and public synonymously.

Research design

This is a qualitative research study based on the principles of phenomenology (Spencer et al., 2020), and our purpose was to understand participants' lived experiences regarding health information-seeking behaviour and the use of PLSs. Our data collection and analysis incorporated principles of reflexive thematic analysis (Braun & Clarke, 2022). This is a method of qualitative analysis by which meaning in the data is interpreted using a reflexive approach that acknowledges the active role of the researcher (Byrne, 2021). This study was approved by the low-risk ethics committee at the University of Sydney, Australia (approval number: 2019/1003).

Data collection

Inclusion Criteria

We focused on participants with a chronic health condition (also known as non-communicable diseases), defined as long-term conditions that often worsen over time and impact an individual's quality of life ('About chronic conditions', 2020). Participants had to be familiar with PLSs or be high users of health information. Participants needed to be adults, i.e., 18 years and over, and able to speak fluent English. Since all focus groups and interview were conducted via Zoom video conferencing, participants needed to have sufficient digital literacy skills to access this platform.

Recruitment

We selected participants using a combination of convenience sampling and purposive sampling, recruiting from two sources. We first accessed a network of consumer representatives from a single health district in Sydney, New South Wales. These were consumers with various chronic medical conditions interested in providing lived experience for research studies. We contacted the network organiser with details of our study, which were distributed to network members. Those interested were able to contact the research team directly for further information. We then advertised the study on Cochrane Engage, which was then called Cochrane Task Exchange ('Cochrane Engage', 2024). This community comprises several thousand volunteers globally who share expertise and experience on projects or tasks. The first author (KG) posted a task requesting participants in our study, outlining our inclusion criteria and including contact details to obtain more information.

We recruited 19 participants for three focus groups and 11 interviews. When determining sample size, we used the concept of information power rather than theoretical saturation (Malterud et al., 2015). Information power is based on the concept that the more information held by study participants relevant to the research question(s), the smaller the sample size needs to be (Malterud et al., 2015). The adequacy of the final sample size was evaluated continuously during the research process, considering a) the relatively narrow study aim, b) the 'strong' interview dialogue (Malterud et al., 2015) from participants who were familiar with PLSs (63.6% having read a PLS in the previous month) and openly shared their views and experiences, and c) the in-depth exploration of narratives through the analysis process. Participants were not renumerated for their participation in this study.

Interviews and focus groups

Of the 19 participants, eight took part in focus groups, and 11 took part in one-on-one interviews. Participants could not participate in both a focus group and an interview. We conducted both focus groups and interviews as there are advantages and disadvantages to both methods of data collection (Busetto et al., 2020). Focus groups are useful for groups of people who already know each other, as was the case for the participants from the local network of consumer representatives. Since most of the other participants did not know each other, the more personal nature of the interview format was deemed suitable and allowed for deep and expansive conversations for the other research participants in this study. (Busetto et al., 2020). Since both focus groups and interviews share the same epistemological assumptions, combining these approaches in a single study has the advantage of providing richer data for analysis (Lambert & Loiselle, 2007). This approach was successfully used in a study of pregnant women with back pain (Foster et al., 2016).

Interviews and focus groups followed a semi-structured interview guide developed and iteratively revised by the research team, drawing on existing literature related to PLSs. Topic areas included general health information-seeking behaviour, PLS preferences in terms of content, length, structure, and wording, the label used for the PLS and the concept of an 'ideal' PLS. During each session, we used visual aids such as example PLSs and a list of terms used by health and medical journals to refer to PLSs. To foster discussion, we deliberately chose PLS examples, including one with sub-headings, bullet points and jargon. In keeping with qualitative methods, this topic guide continually evolved before and during the study in response to emerging learnings. The interview guide and example PLSs are listed in

Appendix C (ii) and C (iii).

All sessions were conducted by KG using the video conferencing tool Zoom and were audio recorded. KG transcribed the recordings using an electronic transcription service and checked them for accuracy.

Data analysis

We used reflexive thematic analysis to analyse the transcripts (Byrne, 2021; Clarke & Braun, 2016). This method is a flexible approach to qualitative research analysis through which we identify and interpret patterns or themes in the data (Byrne, 2021; Clarke & Braun, 2016). Our approach involved the steps included in Table 1. Although we followed these steps in the order below, reflexive thematic analysis is not a linear process (Clarke & Braun, 2016). We moved between assigning codes to theme development several times as we interpreted the data at increasingly deeper levels. KG, DM, and JR (a consumer researcher) were all involved in the data analysis.

Table 1. Steps in reflexive thematic analysis

Step	Description
Familiarisation with the data	KG, DM & JR became familiar with the data, noting key ideas and recurrent themes. This was done by reading transcripts of the focus groups and interviews and listening to audio files.
Data coding	KG, DM & JR reviewed transcripts and tagged sections relevant to the research question.
Initial theme generation	Using collaborative coding, KG, DM & JR made connections within and between codes and developed a system for classifying the data.
Theme development and review	KG & DM continued to review the data and develop themes in alignment with the research question.
Refining, defining, and renaming themes	KG & DM summarised the key points of each piece of theme, established a logical order in which to discuss the themes and

	identified titles for each theme.

Reflexivity

Qualitative research is inherently subjective, and central to our understanding of this subjectivity is the process of reflexivity (Byrne, 2021; Clarke & Braun, 2016). Engaging in a process of reflexivity, we acknowledge that our understanding and experiences inform our analysis. Specifically, KG recognises that, as a person with chronic illness, this lived experience likely impacted the interviews and interpretation of the data. Shared experience, for example, helped build rapport during some interviews. In other instances, it's possible that the way some questions were unconsciously posed or the tone used might have influenced participant responses and the researchers' analysis. In line with reflexive thematic analysis, codes are understood to represent the researcher's interpretations of patterns of meaning across the dataset (Byrne, 2021). As such, we used multiple coders in a reflexive manner (e.g. to sense-check ideas or to explore multiple assumptions or interpretations of the data), aiming to achieve richer interpretations of meaning rather than attempting to reach a consensus of meaning (Byrne, 2021).

Results

Participant characteristics

Demographic characteristics of participants included in this study are shown in Table 2. Most participants were female, aged 60-69, had a university-level education, resided in Australia, and had read a PLS the month before the study. The chronic medical conditions experienced by participants covered eight of the top ten NCDs, with the most common category being cancer. Several conditions impacted how participants processed health information, such as neurological conditions and hearing and visual impairments.

Table 2. Participant characteristics (N=19)

Characteristic	N	%
Age range (years)		
18-39	4	21
40-49	3	16
50-59	3	16
60-69	6	32
70+	3	16
Gender		
Male	3	16
Female	16	84
Highest level of education		
Post-graduate	2	11
University Degree/bachelor's degree	16	84
High School	1	5
Country of residence		
Australia	12	63
United Kingdom	2	11
United States of America	2	11
Germany	1	5
Italy	1	5
Switzerland	1	5
When last read a plain language summary (PLS)		
Within the last month	11	58
Within the last year	6	32
More than a year ago	0	0
I have never read a PLS but I do search for information about my health condition	2	11
Disease category searched most frequently *		
Cardiac	4	10
Cancer	10	25
Musculoskeletal	7	18
Mental Health	3	8
Neurological	5	13
Respiratory	2	5
Digestive Disease	2	5
Skin diseases	1	3
Other	6	15
Diet/nutrition	2	
Weight management	2	
Hypothyroidism	1	
Covid-19	1	

* More than one category could be searched be each participant.

Categories are based on the 2021 data for the global top 10 non-communicable diseases (GBD Compare, 2024).

NB: Categories not searched by participants are not included in the table.

Through the process of reflexive thematic analysis, we developed four themes: (i) 'Accessing information in a competitive landscape of health information'; (ii) 'I really don't see the patient in this at all'; (iii) 'Co-design should be meaningful, not tokenistic' and (iv) 'A way forward: Approach PLSs with creativity'. Across all themes, there were eight sub-themes.

Table 3. Themes and sub-themes

Themes	**Sub-themes**
Theme 1 Accessing information in a competitive landscape of health information	1.1 The dangers of misinformation 1.2 Issues with access
Theme 2 'I really don't see the patient in this at all'	2.1 Uncertainty about the target audience of PLSs: Who is 'the patient' reading PLSs? 2.2 'A fine line': Finding the balance between informing and patronizing 2.3 It must start with the label 2.4 Actionability
Theme 3 Co-design should be meaningful, not tokenistic	Nil
Theme 4 A way forward: Approach PLSs with creativity	4.1 More formats, greater flexibility, and larger audience 4.2 Consider alternate ways of providing PLSs

Theme 1. Accessing information in a competitive landscape of health information

Participants identified multiple sources of health information. See Box 1. All participants felt that accessing reliable health information was important, especially when using it to help make decisions about their medical care. However, participants' narratives relayed the obstacles in accessing reliable health information and determining the trustworthiness of different sources. In this competitive and complex landscape of health information, participants spoke about the importance of PLSs while pointing out barriers to their access.

Box 1. Sources of health information for participants

- Medical professionals
- Evidence libraries e.g., Cochrane collaboration
- Website for specific groups related to medical conditions e.g., Cancer Council
- Social media
- Forums related to medical conditions
- Government websites
- Journals
- Results using key words on search engines e.g., Google
- Support network e.g., family, friends, and colleagues
- Professional associations
- Conferences
- Online education course

1.1 The dangers of misinformation

There was an understanding amongst participants that there is an overabundance of health information available, primarily online. In this context, PLSs were seen to compete with other freely available sources of health information, including websites, blogs and articles posted to social media. These sources are not always reliable and might do more harm than good; several participants expressed concern about the amount of information available and the implications of following poor health advice, such as refusing or discontinuing treatment.

> *"People have access to so much information, but they don't know how to read it or interpret it. Or they find wacky stuff and run with that and are wrong. It's damaging. There are people who refuse treatment for ridiculous reasons, because of stuff that they've read on the Internet who have died and could have survived for many more years than they did." (Participant 18).*

> *"The Facebook groups I'm very interested in…But there's a lot of misinformation there and a lot of working through of people's anxieties and fears. So, I don't go there for information so much anymore." (Participant 7).*

Even when online information is related to research, participants were cognisant that *"the whole story is not always told."* (Participant 6). In such contexts, narratives centred on the dangers of false hope that lay in people not understanding the full scope and implications of research studies.

> *"Yeah, I'm just thinking quite often we get media reports about, you know, cancer research. You know this is the greatest thing since… and then you never hear about it again. But people who are patients with those sort of conditions sort of needlessly get up their (hope), I think it's a little bit cruel in a way they get up their hopes."*
> *(Participant 6)*

1.2 Issues with access

In this competitive health information landscape, participants often stressed the importance of easy access, noting that their *"ideal plain English summary will be something that is easy to navigate to in the first instance" (Participant 5)*. However, participants did not think PLSs were currently easy to access, emphasising two key issues. First, participants spoke about how difficult it is to know where to go to locate PLSs on a specific topic because search engines are unlikely to yield helpful results.

> *"How do you find it? Because we've all said that we tend to do Google searches, online searches … how do you identify that Google tends to be a, uh, a source whereby the person who's paid the most money gets their information in first and…information that's most relevant is probably right at the end three pages on, and people will never find it. How do we find it?" (Participant 3).*

Since most PLSs are published with their accompanying journal articles on the journal website, access is only available to those articles and PLSs that are open access. So, access is not guaranteed even if a journal with a PLS on a relevant topic is located. Most participants did not have journal subscriptions, reflecting that many could not access articles or PLSs behind paywalls.

> *"All the best ones are behind paywalls." (Participant 3).*

> *"Might be interested in how they found them because you know it can be hard to get access. You know if it's not an Open Access article." (Participant 14).*

One participant pointed out that how people access health information in a crisis (including both public and personal crises) differs from non-crisis situations, amplifying the importance of access in such situations. An example of a public crisis is the recent Covid-19 pandemic, which showed the importance of reliable, understandable health information. A personal crisis might include being diagnosed with a chronic or life-threatening health condition, prompting a search for health information.

> *"... 'cause if things like, you know, plain English summaries are hard to get to in a crisis, they're not going to be, they're going to be missed, basically, so I think how people access information in a hurry is different too." (Participant 5).*

Theme 2. "I really don't see the patient in this at all."

Many participants expressed frustration or disappointment that PLSs did not seem to be written with them in mind. There was a sense from participants that the people who read PLSs are different to those that journals target when publishing PLSs. Participants wanted PLSs to provide detailed, actionable information to help make decisions about medical care, expecting such information to be delivered respectfully. This theme reflects participants' views that PLSs that fail to do this may be ineffective at best and alienating to the reader at worst.

2.1 Uncertainty about the target audience of PLSs: Who is "the patient" reading PLSs?

Most of The participants we interviewed were frequent users of PLSs and had a broad understanding of science and health and, in particular, their medical condition. Several people pointed out that people looking for basic information, e.g., someone newly diagnosed with a medical condition, may be unlikely to refer to PLS as a source of knowledge, particularly when so many alternative sources of information are available to them.

> *"…when you look at the sorts of people that are going to be using lay summaries, I think they probably have a fairly, yeah, they may not be researchers. They may not have a lot of detailed knowledge about the science. But you know, they've lived in a complex world and have ways of interpreting lay summaries which is of benefit to them." (Participant 19).*

Participants reflected on the importance of deciding on and understanding the target audience of PLSs. Primarily, this was discussed in relation to determining the language used. Participant 1, for example, reflected that if the intended audience was broad and included those with lower health literacy, then the language needed to reflect that.

> *"You have to decide which part of the patient population you're aiming at. Because if you aim at the ones who've already got health literacy, you don't have to change the words that much, but if you want the full range of consumers to understand what the research is about, you're gonna have to change the language a lot" (Participant 1).*

Participant 17 similarly argued that PLSs in their current form require a level of understanding beyond that of a general audience, with a concern that messages might be misunderstood depending on who was reading them.

> *"I have no problems in reading plain summary, but I think that if my mother read that, the plain summary, not always can [sic] understand the right meaning." (Participant 17).*

2.2. "A fine line": Finding the balance between informing and patronising

Amidst discussion about the target audience, PLS readers described the *"fine line"* between being treated with respect and dignity and feeling as though they are being patronised.

> *"That's a fine line. Being understanding and sounding patronising is a fine balance. So, I have read things that I felt were, you know, patient information that was just it's kind of insulting." (Participant 10).*

> *"I think that the layperson or the reader or the patient isn't stupid… I think don't patronise the reader, don't patronise the consumer." (Participant 7).*

When asked their thoughts on the use of jargon, acronyms, and abbreviations, opinions were mixed. Some participants felt that including some amount of jargon was not only appropriate but preferred. They saw it as acknowledging their knowledge and understanding of medical and scientific concepts beyond the absolute basic. Participant 13 summed up this sentiment by saying, *"I keep making the point that maybe it's too advanced, but I also don't want to say that you know the patients would not understand these things 'cause l don't want you know, like obviously underestimate understanding."*

Other participants felt that the use of jargon was contextual, and its use depended on the journal and article. Some suggested that those who read PLS are more likely to have an advanced understanding of their medical condition, so they would not consider all jargon problematic. One suggestion to cater to a range of readers was to use a technical or jargon word if necessary and put the non-jargon alternative in brackets.

> *"You could put in brackets, for example, heart attack… the person knows what they're reading, 'cause the people know what a heart attack is. They don't know what an acute coronary syndrome is." Participant 4)*

Unlike jargon, most participants agreed that using acronyms was not helpful in PLSs, with a preference for them to be spelt out in full. They noted that since PLSs are usually short pieces of writing, using acronyms can confuse readers unfamiliar with them.

> *"It's a small summary, so if they could have just spelt out the acronym, so there's no point in using the acronyms in something this short." (Participant 5)*

2.3 It must start with the label

Participants reflected on the importance of – and challenges associated with - choosing a suitable label for a PLS, considering the use of language and how words impact the reader. Participants described wanting information written with language that conveys respect and warmth. Here, language was seen as a way of communicating the attitude of the PLS writer towards the PLS audience, with participants recognising that language can alienate the reader or show understanding and inclusivity. Certain words, such as 'patient' and 'consumer', were disliked because they evoked negative emotion, while other terms, such as 'lay', were considered problematic because they have multiple meanings. See Table 3 for a summary of participants' perspectives on the use of labels for PLSs.

Some participants acknowledged that the impact of language and specific terms may be amplified for readers with certain medical conditions or past experiences.

> *" One of the ladies… would be highly offended if anything was labelled as a plain English anything because if it were, she should have the scientific summary. Because she's far too intelligent to be reading the plain English summary…[She] has now got frontal lobe impairment and frontal lobe involvement with her brain tumour, which has changed her personality. Everything's very emotional. Everything is very personal. It's like some personal attack … So, it's an interpretation of specific words like lay or plain English or patient." (Participant 18).*

Most of the discussion from participants centred around why specific labels were disliked. However, a few mentioned some labels they thought would be most successful.

"Plain language summaries is (sic) the best one. Lay summary: I'm not quite sure whether people have a common take on what 'lay' means. So, plain language summaries, plain language. It doesn't, it doesn't mean you're writing up or writing down to your audience." (Participant 19).

Table 4. Perspectives on PLS labels and participant examples

PLS label	Example	Participant
Lay/Lay summary	“I really disliked the “lay” bit.”	5
	“Lay is terrible. You think of a chicken.”	3
	“It feels like it's a very archaic term “lay”. It’s for a layperson”.	5
	“It (lay) might be a difficult word to translate as well. If you have members of the family translating or in yeah, translating for other members of the family.”…”you've really got to be careful that whatever you present is going to be interpretable but also translatable.”	6
	“I didn't know there was in research, there was an actual thing called a lay summary.”	1
	“Only encountered…in [a] religious environment.”	16
	“Lay summaries an awful word in that lay is dreadful”.	3
Patient/patient summary	“Like in the in the patient population how many people are actually comfortable referring to themselves with patients.”	13
	“Using the word patients is not good because not everybody is a patient.”	3
	“I do like ‘summaries for patients’ while some people don't like using the word patient. I think I don't know anybody who finds it offensive. Maybe you know that would be an interesting thing to know how people feel about the word patient. And most people don't know it means victim. But I like it because I know what patient means. It's quick and sometimes I think we've become too sensitive with words like ‘they work, use them’.”	10

	“I know I'm a patient and I know I'm searching for the information as a patient, but somehow you are hurting my...I'm quite (an) emotional person.”	9
Consumer	“A lot of patients get upset about being called consumers.”	18
Clinical	“I think clinical is a bit of a red flag”	3
	“Clinical. That wouldn’t entice me too much.”	16
Plain English summary	“As soon as I see the word lay or plain English. Uh, like plain English, but of course you'd have to or plain language. You'd have to some obviously create plain German summary if you are in a German environment or French or do or Mandarin or whatever you know, but I think it ideally you would have plain English plain language summaries in the in the local language.”	12
	“Plain English summary (example of a poor label) because people think that you're trying to say that they cannot understand English. You’re questioning their intelligence.”	18
Research summary/research lay summary	“Somehow it's indicative.”	9
Plain language summary	*Plain language summaries is (sic) the best one*	19
Author summary	“The author summary is no good because and because it you'd expect the summary of the CV of the author.”	12

2.4 Actionability

Language preferences aside, there was an overarching sentiment across interviews and focus groups that, in their current form, PLSs rarely meet audience preferences for actionable content. Central to this was acknowledging that PLSs should reflect what is most important to the reader. In this context, many participants did not think that providing a basic understanding of a disease or medical condition was the role of a PLS because general information can be easily obtained elsewhere. Most often, participants commented they wanted PLSs that contained practical information with sufficient detail and actionable points to help them make decisions about their health care.

> *"'Here's the next step you should take' and literally spell out what the next thing is to advance this … new information that I have….'Integrate it into my life somehow.'" (Participant 16).*

> *"You sort of need to see their perspective, I mean, as a patient who manages my disease with an awful lot more than just the biological and biological and non-biological drugs. I sort of think it's like I don't really see the patient in this at all." (Participant 12).*

With a focus on actionable content, PLSs were considered an *"empowerment"* tool *(Participant 8)*, however, participants highlighted the need to convey such actions with emotion, and consideration for the reader through the appropriate choice of language.

> *"When you are targeting lay people you have to get it some emotions. Some like some psychological factor. It should be there when I read the lay summary I feel like OK, I'm a physician, but if I am not a physician, I'm totally depressed from this lay summaries (sic), especially with the lay summary end up with like 'this disease has no treatment'." (Participant 9).*

Another use for PLSs was seen in helping to inform decisions about treatment or providing clarity about treatment options. Many participants viewed PLSs are a way of saving time and energy by allowing them to focus on information that applies to their situation.

> *"It'll save me…"In two ways, one is I can quickly evaluate something I may have spent a lot of time on and realise it didn't apply to me. Or quickly evaluate the opposite is to do spend my time on something that that has a good chance of helping me." (Participant 16).*

While many participants described using PLSs to gain personal understanding, others use them as a communication tool with their treating medical professionals, as a tool to feel included in decisions about their health care and support shared decision making (SDM). Some people saw PLSs as something they would print and take to their doctor for discussing some aspect of their treatment, e.g., whether a new medication might be suitable for them.

> *"I could see me taking that article to say my neurologist or rheumatologist and saying you know this this article saying this about this treatment I'm on." (Participant 14).*

Others saw the potential for doctors to use PLSs as a resource to give to patients to help explain difficult concepts.

> *"If you wanted to explain something or give the patient something he would know 'I can print the one page of the summary for this of this paper'. 'I don't have to spend so much time explaining' and it kind of speeds up the process that the patient knows what's going on." (Participant 12).*

Theme 3. Co-design should be meaningful, not tokenistic

Interviews and focus groups highlighted the importance of involving consumers in PLS development through co-design. Here, participants emphasised the importance of good intentions regarding meaningfully engaging in a process in which the consumers' contributions are valued and they feel respected.

All participants agreed that end users of PLSs should be involved in their co-design; however, opinions varied on the level of involvement and the role the end user should play.

Most people thought that end users should be involved in research projects as early as possible because "*to get a good result, we need to involve patients [at an] early stage…in designing research and the language used to express the benefits of the research and how it will impact on people with a disease." (Participant 19).* Irrespective of whether this occurred, there was an overall acknowledgement that – at a minimum – inclusion in the writing of the PLS was valuable.

> *"To involve the end users in writing up the summary will definitely add more perspective to the information." (Participant 11).*

However, despite the perceived need, there was a sense from participants that they are not currently considered a valuable resource for PLS co-design. Participants expressed that they have a lot of experience to offer researchers, and much of their value comes from the unique perspective they bring. Despite this, Participant 14 summarised the concern that consumer co-design *"can become a bit tokenistic at times… We better run it by a consumer so we can tick our consumer box…" (Participant 14).*

There were also discussions about which end-users would be involved in PLS co-design. While some participants thought that members of the patient population with more experience of a specific medical condition were likely to be effective when co-designing a PLS on that subject, other participants were concerned that it does not guarantee they will represent the needs of all population members.

> *"I think that involving end users in design of resources is really important"…"because they are, you know they have such diverse needs."…"like somebody who's had a brain cancer diagnosis who, you know, going through treatment for two or three years has a far better understanding of that world than somebody who's been diagnosed yesterday." (Participant 18).*

> *"I think the only concern is that you know, like how, how do you determine which, like you know whoever like, are they actually representative of the patient population?...My*

> *biggest concern is if the person is not taking into account all the different, you know, the disparate experiences and views of the patient population, and that obviously depends on context." (Participant 13).*

Building on the topic of consumer representation, Participant 2 noted how important it is to stay connected to the broader patient or consumer community, reflecting on how her perspectives and the type of information she searches for have changed since receiving a diagnosis.

> *"When you're representing consumers… it's really important that you stay current with consumer views because what happens then, on a cancer diagnosis, is how I felt in 2004 and how I feel now is completely different. And the information I seek out now is completely different". (Participant 2).*

Theme 4. A way forward: Approach PLSs with creativity

This theme reflects the aspirations of PLS readers for PLSs in health journals to be more flexible in their approach, accommodating the needs of more people. This involved forward thinking and considering novel ways to deliver PLSs.

4.1 More formats, greater flexibility, larger audience

Acknowledging that there is not likely to be one PLS format that suits all readers, participants questioned whether a text-based PLS is enough. Many reflected on the potential benefits of including visual media - such as video or graphical summaries - as an adjunct to text-based PLSs to offer choice and suit the varying needs of PLS readers. Providing a selection of formats was also thought to open the information to a wider audience.

> *"Having those options so that everyone kind of can choose you know what they find easiest and most engaging." (Participant 14).*

> *“I think some kind of hybrid would be good I guess because we know that just people learn or absorb information in different ways. Listening to the video and then reading the notes or I know myself if I want to get a point, I've got to read something more than once and receive it in more than one way for it really to stick I think.” (Participant 16).*

> *“I would probably personally prefer a mixture (of formats) because that just means more flexibility of how I would like to read the summary, like I mean, either read or watch or look at the summary. I appreciate that the choices that I've been given and the flexibility of different formats.” (Participant 11).*

In the context of this discussion, some participants acknowledged that having a chronic illness can impact how information is processed. For example, people with altered cognition or vision pointed out the need for information to be presented in an accessible way. For PLSs to be more useful and more widely adopted, better accommodation of the varying needs of readers is vital. Videos were seen as a potentially useful educational tool, with advantages for people from non-English speaking language backgrounds and those with altered cognitive function for whom text-based PLSs might be a high cognitive load.

> *"I'm all for making things more accessible for all kinds of people who have all kinds of either literacy or communication differences, cultural differences, differing abilities". (Participant 15).*

> *"So, it's really thinking more about universal design." (Participant 18).*

4.2 Consider alternate ways of providing PLSs

A few participants wanted to see journals consider creative ways of publishing PLSs that would make them more accessible. One participant suggested a website containing PLSs or a journal that only produced PLSs.

> *"It would be worth having a journal which publishes lay summaries. Yeah, just lay summaries. Yep. With links to the original articles because patients are on the Internet." (Participant 18).*

Discourse with participants revealed multiple concerns with how PLSs are currently written and published. Although the perspectives and experiences of participants with PLSs differed, one aspect of PLSs was shared universally. It was expressed by Participant 11: *"I think the most important is the summary is actually summarising the contents of the journal article, like how relevant or how well the summary… summarises the actual journal article".*

Discussion

Results of this qualitative study with participants living with chronic conditions from six countries suggest that PLSs, although a valuable source of reliable health information, do not fully meet the needs of their audience. Our interviews and focus groups revealed a fundamental lack of clarity about the intended purpose of PLSs and their intended audience. Many of the aspects of PLSs participants told us they want considered, may not be evident to academics or journal publishers, i.e., people who write and publish PLSs. This includes the importance of the PLS label, the need for actionable content, and the recommendation to vary the reading level depending on audience needs. Participants identified some solutions for addressing this lack of clarity. Of key importance was ensuring consumer involvement in the co-design of PLSs was taken seriously, with their contribution appreciated and valued. Creative ways of providing PLSs were suggested as ways of addressing concerns over access, as well as catering for the needs of more people.

This qualitative study builds on previous research that reported the preferences and perspectives of consumers regarding PLSs (Glenton et al., 2010; Kirkpatrick et al., 2017; Santesso et al., 2015). These studies reported varied results, with some finding that consumers unfamiliar with research language, such as confidence intervals and quality of evidence, preferred PLSs in which large amounts of information were broken down with sub-headings. They also noted the need for headings to be written in plain language.

In contrast, our study's findings included those related to how participants viewed the use of jargon and desired PLSs that inform without patronising them as readers, highlighting the need to understand and clearly communicate to the target audience of PLSs. People who read PLSs may fall into the category of the "informed patient" (Kivits, 2004, p2). This term describes those motivated to seek health information through sources such as the Internet rather than relying on that supplied by their treating medical practitioner (Kivits, 2004). Our data suggests alternative formats might also help to cater to a broader range of consumer information needs and preferences. Such formats could include audio summaries such as podcasts and visual summaries such as infographics.

Previous work on the author instructions for writing PLSs (Gainey et al., 2023; Haughton & Machin, 2017; Stoll et al., 2022) showed a wide variation in the PLSs instructions between journals and publishing groups. However, no study located instructions referring to PLS content that is actionable. This is notable because actionable content is one aspect of PLSs that participants brought to our attention as being of importance. Although some articles will not have actionable content directly related to consumers, our study suggests that it is an important aspect of PLSs that is currently missing, so inclusion in PLS guidelines would benefit PLS readers.

Strengths and limitations

Our study benefited from videoconferencing to engage with participants from outside our local area, reaching participants from five countries outside Australia. Video conferencing helped the interview progress naturally and provided file and screen sharing functions, which enabled the interviewer to use visual aids such as example PLSs, which were all sourced from health and medical journals. However, we were limited to interviewing participants who spoke English, so that we may have missed views from people with culturally and linguistically diverse backgrounds. Since most (84%) participants were female, the study may have benefited from including more male participants. We also note that only one participant had obtained a university degree or higher. This may indicate that this cohort is more likely to read PLSs, participate in health research, or both. Although the choice to use both focus groups and interviews in this study was justified, combing qualitative methods can have disadvantages. This study only included PLSs from health and medical journals; however, journals from other disciplines publish PLSs. Our results should only be interpreted within the context of PLSs from health and medical publications. Although other studies (Glenton et al., 2010; Kirkpatrick et al., 2017; Santesso et al., 2015) have reported the perspectives of consumers on aspects of PLSs, this study involved a larger number of participants and reported a more detailed thematic analysis to understand the main perspectives of participants about PLSs.

Implications and future directions

The growing body of research on using PLSs has highlighted the need for standardised PLS instructions or guidelines with a systematic review of PLS theory, guidelines, and research concluding that current PLS guidelines are not evidence-based (Stoll et al., 2022). The authors proposed a conceptual framework for PLS guidelines and argue that guidelines should be developed with the aim and target audience of the PLS in mind, as these factors are closely linked (Stoll et al., 2022). Many guidelines for writing PLSs in health journals suggest that the use of jargon should be avoided (Gainey et al., 2023). Variations in preferences for medical terms and jargon identified in this study indicate that guidelines about the use of jargon may need to take a more nuanced approach. Clarity about the purpose and audience of PLSs would help inform the appropriate jargon level.

A recurring sentiment expressed by participants was the importance of making PLS content actionable. This meant ensuring that the content provided practical information to help guide readers to make healthcare decisions, often in conjunction with their treating medical practitioner. PLSs in most health and medical journals are quite short, most ranging from 100 to 250 words (Gainey et al., 2023), except for those produced by Cochrane, which are up to 850 words (Higgins et al., 2024). PLS authors need to consider how best to use this limited space to ensure they convey key actionable messages about the research study clearly with an appropriate level of jargon. This task requires skills different from those needed to write the research article. Guidelines for writing PLSs could be supplemented with training and consumer input to help researchers write more effective PLSs.

Consideration for the language used PLSs was frequently discussed by participants, with many expressing disappointment or frustration when language is overlooked. A notable finding was that participants wanted PLSs to be written with more warmth and emotion. This is important as it not something that might be obvious to researchers, so efforts to assist PLS authors to write actionable PLS that use friendly, warm language could increase their impact and usefulness.

Without an evidence base to draw from, it is difficult to know how much consumer input in PLS development might have affected the instructions that journals and other agencies produce to aid authors in writing a PLS. The PLSs produced could likely be improved with consumer input, and our study shows that this is something consumers want to happen. This could make PLSs a more helpful source of health information for consumers, particularly those with chronic illnesses.

Despite open access options for PLSs such as those found in the Cochrane Library ('Cochrane Library', 2025), participants spoke little about such repositories other than as a source of general health information. This indicates the need for a more targeted way of promoting PLSs to potential readers. For example, PLSs are ideal for sharing on social media, providing an opportunity for both authors and journals. Doing so would offer PLSs that are accessible to all and can more readily be shared with others.

Future studies could build on this qualitive survey by including larger numbers of PLS readers more diverse geographic, cultural backgrounds, education and employment backgrounds. Utilising cognitive interviews with readers of PLSs could provide a greater understanding of how they interpret the information contained in PLSs, helping researchers to optimise the process of writing PLSs.

Conclusion

PLSs have the potential to be a means of communicating the findings of health research to a general audience. Publishers of health journals need to reflect more critically on the target audience for PLSs and state it explicitly. Once the target audience for PLSs is clear, publishers could use some creative methods to develop solutions for delivering PLSs that better suit the people who read them.

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Statements and declarations

Declarations of conflicting interest:

Karen M. Gainey, Kirsten J. McCaffery and Danielle M. Muscat have completed the International Committee of Medical Journal Editors (ICMJE) uniform disclosure form at http://www.icmje.org/coi_disclosure.pdf and declare no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous 3 years; and no other relationships or activities that could appear to have influenced the submitted work, with the exception of Health Literacy Solutions Pty Ltd, at which Kirsten McCaffrey and Danielle Muscat are directors.

Ethical considerations

This study was approved by the low-risk ethics committee at the University of Sydney, Australia (approval number: 2019/1003).

Consent to participate

Consent was provided via a written consent form.

Consent for publication

Not applicable.

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Data availability statement

The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

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Chapter 5. What do editors of medical journals think about opportunities and barriers for advancement in the publication of plain language summaries? A qualitative analysis

This chapter reports a qualitative study of editors from health and medical journals. The study's purpose was to understand better the publication process to uncover potential barriers and facilitators to the publication and dissemination of PLSs. As noted in the Introduction, similar to the perspectives of end users of PLSs from the previous chapter, journal editors' views have been largely overlooked.

The methodological choices made for the previous qualitative study in Chapter 4 were also applied to this study. In this study, I sought to understand the opinions and perspectives of participants through their lived experience in their roles as journal editors and publisher. For this reason, a phenomenological approach was used. I used reflexive thematic analysis for data collection and analysis to capture and report the richness of participants' experiences. Findings from chapters two, three and four helped inform the interview guide for this study.

Chapter five has been submitted to a peer-reviewed journal and is currently under review.

Abstract

Background: Plain language summaries (PLSs) are short summaries of research articles written for a diverse audience using plain, easy-to-understand language. Although many health and medical journals have adopted them, we have a limited understanding of how journal editors view them. This remains a substantial gap because of the role journal editors play in the decision-making process for the publication, implementation, and dissemination of PLSs.

Objectives: To address this evidence gap, this qualitative study aimed to (a) gain a better understanding of the decision-making process that governs the publication of PLSs at the journal and publishing group levels; (b) explore attitudes and perspectives of journal editors towards PLSs; and (c) identify and explore barriers and facilitators to the implementation of PLSs by journals and journal publishers.

Methods: Following the principles of reflexive thematic analysis, we conducted semi-structured interviews with 20 participants representing 23 journals and eight publishers/publishing groups.

Results: Through our analysis, we developed five themes: (i) When good intentions clash with practical realities; (ii) Whose job is it anyway?; (iii) A cautiously optimistic approach to support from artificial intelligence (AI); (iv) Blind spots and broken loops; (v) A 'One size fits all' approach doesn't work. Discussions with participants highlighted the differing approaches taken by journals to prioritising PLSs, often governed by barriers such as resource allocation and the need for standardisation within publishing groups. While many participants showed initiative to overcome barriers, often in their own time, they noted challenges associated with a lack of readership data and role clarity in the PLS production and dissemination pipeline. Opinions were mixed on the integration of AI and alternate formats for PLSs.

Conclusions: By embracing technology such as artificial intelligence, integrating innovative formats and exploring distribution channels, including via consumer groups and social media, journal publishers can help elevate and expand the reach of PLSs.

Plain language summary

Why Was This Study Done?

- Many health and medical journals include plain language summaries, however little is known about the views held by journal editors about plain language summaries.
- We wanted to better understand how decisions are made, and anything that might assist or interfere with the production, use and distribution of plain language summaries.

What Did the Researchers Do and Find?

- We held one-on-one interviews with 20 people who were a mix of journal editors and publishers.
- Most participants thought plain language summaries were an important way of making health research accessible to more people, however some editors had more support from their publishers and resources available to help authors and make the most of their plain language summaries.
- Editors understood that plain language summaries have a diverse audience e.g., patients/carers, health professionals, researchers and policy makers, so they could reach more people by using creative formats and distributing them in novel ways.

What Do These Findings Mean?

- More needs to be done to support PLSs across health and medical journals, and publishing groups.
- Artificial intelligence could help authors and journals produce more PLSs, but humans are needed to make sure there are no errors.
- Making PLSs easier for readers to find will help deliver accessible research findings to a more diverse group of people.

Introduction

Since the first medical journal was published in 1793, health and medical journals have evolved, introducing new features and formats (Narayanan et al., 2018). One such feature is plain language summaries (PLSs), which are short summaries of research articles written for a diverse audience using plain, easy-to-understand language (Wada et al., 2020). The adoption of PLSs has steadily increased since they were first introduced in health and medical journals in the 1990s (Haughton & Machin, 2017). Interest in PLSs has also grown, with research focusing on varying aspects, including PLS characteristics (Lang et al., 2025; Maurer et al, 2021; Zarshenas et al., 2023), the perceptions and preferences of PLS readers (Gainey et al., 2025; Katz et al., 2025; Nunn & Pinnfield, 2014; Pushparajah et al., 2018) and the effectiveness of varying formats (Bredbenner & Simon, 2019; Pferschy-Wenzig et al., 2016; Silvagnoli et al., 2022). A systematic review published in 2022 (Stoll et al., 2022) found 90 articles that reported on criteria and outcomes of PLSs. Most articles reported recommendations on the use of language (e.g., avoid jargon and use passive voice), PLS structure (e.g., suggested length and the use of headings), and PLS content (e.g., guidance through "Who, What, Where, When, Why and How?" questions (Stoll et al., 2022. p12). However, study designs were too heterogeneous to identify definite criteria for high-quality PLSs, and few studies identified the effects of various PLS features on accessibility, understanding, knowledge, communication of research, and empowerment (Stoll et al, 2022).

Research that has focused on the implementation of PLSs has been much more limited. We conducted a scoping review in 2023 (Gainey et al., 2023) and found that very few journals (27/526, 5.1%) publish PLSs, with most of these being an optional inclusion. Guidelines for writing PLSs vary markedly in terms of detail and scope, which is a similar finding to other research studies (Haughton & Machin, 2018; Narayanan et al. 2018). When we assessed compliance with PLS guidelines, we found varying levels of compliance between published PLSs and the guidelines of the journals in which they were published, with areas for improvement regarding the use of jargon, readability, and the content of the PLS (Gainey et al., 2024). Qualitative research with consumers also suggests that, even when implemented, PLSs are not always easy to find or access, particularly in an increasingly crowded online health information landscape (Gainey et al., 2025).

This emerging work suggests that while some aspects of PLSs have been well studied, we lack a fundamental understanding of other areas. The perspectives of health and medical journal editors about PLSs have not been well explored. A review of the literature yielded only one study conducted by Open Pharma to determine whether the perspectives of journal editors aligned with the Open Pharma recommendations for PLSs published in 2021 (Bárόniková et al., 2024). Since most (19/26, 73%) journals analysed in this study did not permit PLSs from authors and only seven journals had published PLSs previously, decision-making around and barriers and facilitators to their implementation were relatively unexplored (Bárόniková et al., 2024). This remains a substantial gap because of the role journal editors play in the decision-making process for the publication, implementation, and dissemination of PLSs. To address this, the aims of the study were to:
a. Gain a better understanding of the decision-making process that governs the publication of PLSs at the journal and publishing group levels.
b. Explore attitudes and perspectives of journal editors towards PLSs.
c. Identify and explore barriers and facilitators to implementing PLSs by journals and journal publishers.

Methods

Research design

To address our exploratory research questions, we adopted a phenomenological qualitative research approach (Spencer et al., 2020). Phenomenology is an approach aimed at understanding the lived experience of others (Neubaurer et al., 2019). This study was approved by the low-risk ethics committee at the University of Sydney, Australia (approval number: HE001170).

Inclusion Criteria

We were interested in exploring the views of editors, associate editors and editorial staff from leading health and medical journals. We aimed to include at least one editor from each of the top five publishing groups based on journal count (Academic Publishers and Scholarly Journals, 2025). These journals are Springer, Taylor and Francis, Elsevier, Wiley and SAGE. Our inclusion criteria were:

- The job title is Editor-in-chief, associate editor or editorial staff
- Works or volunteers for a journal that publishes health or medical research articles
- Works or volunteers for a journal that publishes text-based PLSs or similar, e.g. key messages, highlights
- Works or volunteers for a journal that publishes research articles in English
- Self-reported ability to participate in an English-language interview

To engage with editors from journals that publish in health literacy and health communication (given the relevance to PLSs), we included editors from these journals even if they didn't publish PLSs.

Recruitment

We selected participants using a combination of convenience, purposive and snowball sampling, recruiting from four sources. We began with a list of journals we knew PLSs had been published from our previous study (Gainey et al., 2023). We added health and medical journals from the top five publishing groups listed above and those in the area of health literacy and health communication. From this list, we obtained the names and email of editors from publicly available information sources such as journal websites and public profiles. We emailed them with information about – and an invitation to participate in – our project. If we did not receive a response, we sent a reminder email two weeks after the initial email.

Second, we distributed an email via the research team's professional networks. These networks comprised professional and personal contacts of the research team, i.e., journal editors known to the research team. We contacted these editors in the same manner as all other potential study participants, using the recruitment email and two-week follow-up protocol. Third, we developed an advertisement for the study for use on social media websites such as LinkedIn or X (previously Twitter) and an advertisement for Cochrane Engage, a community of several thousand volunteers globally who share expertise and experience on research-related projects or tasks. Fourth, we used snowball sampling to ask participants for referrals after each interview. All potential participants obtained via referrals were contacted in the same manner as previously outlined.

Interested participants were directed to a survey hosted on Qualtrics to register interest in the study, view the participant information sheet and consent form, and complete demographic questions. After the research team checked for eligibility, those eligible for the study were emailed to arrange an interview date and time.

Sample size

We used the concept of information power rather than saturation to determine our sample size (Malterud et al., 2015). Information power is based on the idea that the more information participants hold about the research question(s), the smaller the sample size needed (Malterud et al., 2015). During data collection, we continuously evaluated the sample size, balancing criteria suggested by Malterud and colleagues (2015). See Table 1 for a description of our process for considering information power and sample size.

Table 1. Considerations for determining sample size using information power

Items that impact information power	Explanation	Application in the current study
Study aim	A broad aim requires a larger sample size than a narrow aim	Our study aims are quite narrow, with a discrete focus on the publication, implementation, and dissemination of PLSs in health and medical journals.
Sample specificity	The more specific the experiences & knowledge of participants, the smaller the sample required	We recruited editorial staff from journals that did and did not publish PLSs, as well as those working directly with publishing groups, indicating high sample density.
Established theory	Stronger and more established theories used, smaller sample size required.	This study is based on the theoretical principle of phenomenology, with the interviews accessing the perspectives of editorial staff based on their

		experiences with the decision making process involved in publishing PLSs.
Quality of dialogue	Stronger dialogue in interviews, small sample size required.	This was the fourth study by the interviewer (KG) in the area of PLSs published by health and medical journals and the second qualitative study involving interviews, so the interviewer (KG) was experienced in the subject matter of the interviews and the process of qualitative interview technique. Coupled with the enthusiasm of participants to share their experiences, this yielded strong, high quality interview dialogue.
Analysis strategy	Where a strategy is designed to provide an in-depth analysis of narratives, a smaller sample size is required.	Using reflexive thematic analysis, a thorough exploration of the data was conducted.

Data collection

Interviews were conducted between November 2024 and March 2025. Interviews followed a semi-structured interview guide developed and iteratively revised by the research team, drawing on existing literature related to PLSs. The interview guide is available as Appendix D (ii). The scope of questions included topics related to:

- Decision-making for publishing PLSs
- The intended audience for PLSs
- Guidelines for PLSs and compliance
- PLSs and peer review
- The use of tools involving artificial intelligence for producing PLSs
- Alternative ways of presenting PLSs
- The future of PLSs in journal publishing

All interviews were conducted by the first author (KG), a public health researcher trained in qualitative methodologies, and were audio recorded and transcribed using the video conferencing tool Zoom. Transcripts were checked for accuracy by the first author, and any identifying information was removed from interview transcripts. We offered all participants the opportunity to review a copy of the raw transcript to reflect on their responses with the interviewer (KG), to provide additional insight, or to correct any misunderstanding. For the two participants who chose this option, we emailed the raw transcript within two days of their interview. All participant comments or feedback were considered part of the transcript and included in the data analysis.

Data analysis

We used reflexive thematic analysis to analyse interview transcripts (Byrne, 2021; Clarke & Braun, 2016). Using this approach to qualitative research analysis, we identified and interpreted patterns or themes in the data (Byrne, 2021; Clarke & Braun, 2016). Our approach involved the steps included in Table 2. Although we followed these steps in the order below, reflexive thematic analysis is not intended to be a linear process (Malterud et al., 2015). We moved between assigning codes to theme development several times as we interpreted the data at increasingly deeper levels. KG and DM were involved in data analysis.

Table 2. Steps in reflexive thematic analysis

Step	Description
Familiarisation with the data	KG & DM became familiar with the data, noting key ideas and patterns. This was done by reading transcripts of the interviews and listening to audio files.
Data coding	KG & DM reviewed transcripts and tagged sections relevant to the research question.
Initial theme generation	Using collaborative coding, KG & DM made connections within and between codes and developed a system for classifying the data.
Theme development and review	KG & DM continued to review the data and develop themes in alignment with the research question.
Refining, defining, and renaming themes	KG & DM summarised the key points of each piece of theme, established a logical order in which to discuss the themes and identified titles for each theme.

Reflexivity

Qualitative research is subjective, and the process of reflexivity enhances our understanding of this subjectivity (Byrne, 2021). By engaging in reflexivity, we acknowledge that our knowledge and experiences naturally inform our analysis and that the complete elimination of bias cannot be achieved in qualitative research and, more importantly, should not be an aim (Clarke & Braun, 2016). Engaging in the process of reflexivity, we acknowledge that our analysis is informed by our knowledge of PLSs, belief in the importance of clear communication, and experiences as both health consumers and editors. For this study, KG wrote analytic memos after each interview, which served as opportunities to reflect on what worked during the interview, what could be improved and any patterns or strong impressions from the interviews (Saldana et al., 2020), and we held regular meetings to discuss findings and critically reflect on our positionality and representation of research findings. In reporting the results, the study also aimed to centre participants' words descriptively to preserve their intention.

Results

Participant characteristics

Characteristics of participants included in this study are shown in Table 3. Most participants were male, resided in the United Kingdom or Australia, had worked as an editor for at least five years, and reported making up to 10 editorial decisions weekly. Editors were most commonly affiliated with Taylor and Francis and Wiley publishing groups.

Publishing characteristics

Given that some participants represented more than one journal, a total of 23 journals were represented by the 20 study participants. Most (N=17) participants represented a journal, with 5 representing a publisher/publishing group and two participants representing both. Almost half of the journals represented (N=11) were affiliated with a professional society. Of the journals represented, half (N=11) used the label 'plain language summary', and slightly more than half (N=14) required a PLS with the manuscript, i.e., it was mandatory.

Table 3. Participant characteristics N=20

Characteristic	N (20)	%
Age range (years)		
18-30	1	5
31-45	7	35
46-60	10	50
60+	2	10
Gender		
Male	11	55
Female	9	45
Country of residence		
United Kingdom	7	35
Australia	6	30
United States of America	4	20
France	1	5
Germany	1	5
Russia	1	5
Journal publisher [a]		
Springer	5	NA
Taylor & Francis	4	NA
Elsevier	5	NA
Wiley	5	NA
SAGE	5	NA
Other	7	NA
Job Title [b]		
Editor-in-chief/Deputy Editor-in-Chief	10	50
Associate Editor	4	20
Senior Editor	1	5
Production Editor	1	5
Other	4	20
Years in current position		
1-3	5	25
3-5	6	30
5-10	6	30
10+	3	15
Approximate number of editorial decisions/week		
<5	5	25
5-10	5	25
10-20	1	5
20-50	4	20
50+	0	0
Varies	1	5
Unsure	4	20

a. Some participants represented more than one journal.

b. Job title recorded by participant in Qualtrics form.

Through the process of reflexive thematic analysis, we developed five themes: (i) When good intentions clash with practical realities; (ii) Whose job is it anyway?; (iii) A cautiously optimistic approach to support from artificial intelligence (AI); (iv) Blind spots and broken loops; (v) A 'One size fits all' approach doesn't work. Across all themes, there were 15 sub-themes.

Table 4. Themes and sub-themes

Themes	**Sub-themes**
Theme 1 When good intentions clash with practical realities	1.1 Editors are purpose-driven to implement change 1.2 Negotiating change 1.3 Uniformity and Autonomy 1.4 Going "above and beyond" in the context of resource limitations
Theme 2 Whose job is it anyway?	2.1 Authors 2.2 Editors 2.3 Peer reviewers 2.4 Consumers
Theme 3 A cautiously optimistic approach to support from artificial intelligence (AI)	3.1 A good starting point 3.2 The responsible use of AI 3.3 Does AI pose unforeseen risks?
Theme 4 Blind spots and broken loops	4.1 Who is the actual target audience? 4.2 Evaluation is difficult without readership data
Theme 5 A 'One size fits all' approach doesn't work: the need for novelty	5.1 Novel formats 5.2 Novel dissemination routes

Theme 1. When good intentions clash with practical realities

1.1 Editors are purpose-driven to implement change

Common to all interviews was an appreciation of the value of PLSs in supporting understandable health communication. While many participants expressed that they "*believed passionately*" or were "*very enthusiastic*" about PLSs as a form of communication to reach a broader audience, at minimum, other editors that we spoke to acknowledge the goal of PLSs "*to make sure all are served and everybody understands what is written in* *there"*. Even the few participants associated with journals that did not produce PLSs spoke about some of the perceived benefits from their perspectives, including expanding reach and readership:

> *"Having a broader readership, I think, can only help a journal." (Participant 11).*

1.2 Negotiating change

In this context where participants placed value on PLSs, many reported 'taking it on themselves' to try to implement PLSs through their editorial roles, with some even having initiated the implementation of PLSs within their tenure.

> *"And so, it happened because the editors believed passionately it was really important, we took it on ourselves to do it." (Participant 3).*

> *"So, you know, we've been very enthusiastic about a number of different innovations, including….obviously the plain language statements that you've seen. But that is all done by the editors negotiating that with [publisher X] to ensure that it can happen. If we didn't advocate for it, it wouldn't happen." (Participant 17).*

When editors reflected on the process they went through to implement change, they reported varying levels of support from their journal's publisher. Some editors relayed how they had to negotiate with or "*convince*" their publisher of the value of PLSs. At times, such negotiation was centred around demonstrating to the publisher that any change was financially justified.

> *" So, we'd have to convince the publishing company … you know, this is worth investing in, and their response will be 'Show me how it affects our bottom line". (Participant 13).*

> *"For them, most of our requests have a cost, right?…But if they can see that it makes a difference to downloads, citations or the prominence of the journal, they're*

> *supportive. Okay? So, you know, it's, that's very, I mean, we have a good relationship. But it's a very transactional relationship." (Participant 17).*

1.3 Uniformity and Autonomy

For others, change was complicated by existing structures and processes established at the publisher level. Although many editors were open and supportive of approaches to encourage authors to submit PLSs, they had to work within the parameters of their journal and/or publishing group. A tangible example of this was the constraints that pre-defined submission portals posed for PLS implementation, i.e., there not being a separate field for PLSs in the submission portal as there is for the manuscript abstract and other items. Publishers' preference for their journals to have a distinct, unified style was also discussed in the context of PLS author instructions. Some editors felt that this prevented them from being able to offer PLSs in a way that best suits the journal's target audience.

Given such constraints, some participants we spoke to felt that change needed to occur at the publisher level to "*harmonise the publishing practices of all journals, so they all fit best practice" (Participant 6).* Others, however, seemed to be more autonomous and were able to provide examples of times in which they were able to instigate change easily.

> *"We did want to introduce plain language summaries as a requirement in the author guidelines, and they were quite supportive of that. It wasn't a standard thing for them, at least not at that time." (Participant 1).*

Discussions about autonomy were often held in the context of broader reflections on the relationship between each editor/journal and their publisher and whether a publishing group or a medical society-owned journal. Those journals affiliated with a society tended to have more autonomy than those owned by a publishing group. Editors noted how this autonomy enabled them to enact change more quickly and easily.

> *"My contract is with the Society to act as the editor-in-chief. What that means, though, is that I, via the Society, have had a fairly open license to shape the journal's*

> *editorial policies as I see fit. And that was true for the editors before me because this is not a publisher-owned editor. This is a Society owned journal. So, the highlights were something that I put in place when I became editor-in-chief." (Participant 8).*

> *"Kind of frustrated…with regard to the homogenisation of what publisher X is doing with their journals just so they have consistency in the way they look without being very supportive of the tailoring it, how we tailor it to our situations in terms of what our aims and scope are. Now, they give us some latitude to do that, but it's within the instructions to the authors, which are just almost like suggestions….So, we have a great deal of control over content, but we do not have much control over how things are structured in the manuscript. That's where they're one size fits all. And we don't have a lot of control over what budget we get." (Participant 13).*

A few participants were associated with journals that did not produce PLSs and shared their thoughts on why this was the case. One person suggested that the journal's actions demonstrated that they saw no purpose in including PLSs in their journal because their only audience was other professionals, i.e. medical professionals and researchers, not experts in the particular field covered by the journal. For another participant, the decision not to include PLSs was due to a lack of prioritisation. Both participants thought their respective journals missed an opportunity to reach a broader audience by not including PLSs, especially when publishing open access.

> *"I think that on many of these journals, including mine, there are too many clinicians, understandably, who are domain specific. So, ours is a [X] journal. It's read by [Xists] or specialists in [X]. Some people can access it, but they're not the intended audience. So, you know what, this is not really an issue. It's not really a, there are other things that need to be discussed. There are other priorities, so I think that's a little bit short-sighted…. So, you know, I'd like to. But I think that's what holds back our journal and other journals. It's simply not seen as a priority." (Participant 11).*

> *"I don't think they [the publisher] see the journal, as even though it's open access as this public facing. I don't think they've moved progressed to that level. And I get that vibe also from attending the conference that you're there to communicate your science with other scientists, and that's the audience that you're communicating with. So, having a like, there's no for them, maybe, that they don't see a purpose of having a plain language summary, even though it's an open access journal, and so many other people are reading it. But yeah, I find that society quite insular." (Participant 15).*

1.4 Going "over and above" in the context of resource limitations

Many editors reported operating with limited resources, leading to the need to prioritise projects and activities, with those related to the delivery of PLSs often receiving less attention. Participants often expressed that their time in relation to PLSs was "*over and above*" what they considered their regular editorial role. Given existing constraints on time and resources, this stood as a challenge to implementation and sustainability.

> *"When I worked at [journal X], we had a lot of conversations about, do we have the time to do this? How are we going to do this? Who's going to do this? … And you know, we ended up writing them, you know, over and above what our normal job was." (Participant 3).*

> *"She's just doing that on her own, I think, like not from the Journal, and so on. So, you know, it's a resources question. Who's got the resources and the skill and the interest." (Participant 16).*

Conversations about resource limitations extended beyond human resources. Many participants reflected on the "*shoestring*" budgets allocated to their journals and discussed how they needed to weigh decisions about PLSs in such contexts. There were clear opportunity costs to generating PLSs that editors considered in their daily decision-making.

> *"I suspect that, for example, a lot of specialty journals which are run on a shoestring don't have the capacity to even generate plain language summaries." (Participant 3).*

> *"With regards to the resources we have and the benefits we might get out of those resources… that is not a priority." (Participant 2).*

Given the multiple tasks editors had to juggle, processes involving PLSs, such as author instructions and peer review, were rarely reviewed once put in place.

> *"Are the headings that we have there the right ones? I don't know. But you know, we've got a whole, I've got a whole process of things that I'm doing at the moment, and this serves a function. So, we've decided to leave them as they are at the moment." (Participant 3).*

Theme 2. Whose job is it anyway?

Interviews touched on the people involved in the publication pipeline, including authors, editors, peer reviewers, and consumers and their role (or lack thereof) in PLS development. A lack of clarity and ownership in terms of PLS production was thought to contribute to the variable quality of PLSs.

2.1 Authors

Participants in our interviews generally thought that authors were not proactive about including PLSs in their research articles or developing them to a high standard. This was attributed to a lack of familiarity with PLSs or plain language best practices and a lack of priority. Complicating this was the observation that many authors do not seem to read the author instructions for the journal, either submitting a PLS that isn't suitable or not submitting one at all.

> *"Because, in reality, people don't read the author guidelines. So that's why we often get the 1st versions without having a plain language summary at all…. Quite often, they will just sort of do it as a bit of an afterthought, I think, and they'll just do it to*

> *get through the requirements, but they're not really thinking about 'Is this understandable for an average person'? And some of them, I guess that's not really familiar to them…" (Participant 1).*

While there was an acknowledgement that *"there are some topics…that are extremely difficult to put into PLSs like … survival curve, extrapolation, mathematics in multi microsimulation models…"* the general sentiment was that, irrespective of the topic, authors are often tempted just write the PLS with minimal effort so the manuscript can be published. Reflecting on the submission process, participants noted that PLSs are frequently the last part of the manuscript that authors write and are often a direct copy of other sections, such as the abstract or conclusion, with little effort to consider the audience.

> *"The authors not (sic) necessarily understand what is meant with the patient summary. So, we very often just get a copy-paste from the conclusions of the abstract, which obviously is not the aim behind it. And I think there's a clear problem with the understanding of a scientist of what might be plain language." (Participant 2).*

> *"They've done the work…they get to the end of the review, and they think, 'Oh, I've got to do this now.' And it is hard. It's a skill … actually being able to write in plain language is really difficult." (Participant 4).*

Participants in this study reflected on the authors' varying levels of enthusiasm for PLSs. While some felt that authors most likely do not enjoy writing PLSs given that it's *"just such a painful thing… it's the thing that you hate the most",* other editors recognised that not all authors find writing PLSs a difficult or unpleasant task. Of the participants we spoke to, people felt that the distinction could be attributed to the value authors attributed to PLSs to communicate their research to more people.

> *"It's hard to put into words. But when a group of authors does the PLS because they want to, it's a different quality of PLS than when they're forced to….if it's written from*

> *like that good spirit like, we want to make this research understandable." (Participant 20).*

Likewise, editors commented on the notable difference in the quality of PLS written by professional medical writers. Due to their scope and audience, some journals attract more articles from authors with industry funding and a budget for a professional medical writer to produce a high-quality PLS. Editors commented that they rarely suggest changes to these PLSs. However, one editor pointed out that authors might be the best people to write the PLS because they are most familiar with the research and potentially have the most to gain.

> *"Papers that are sponsored by Pharma companies, they'll go through lots of levels of approval before they come to me. They'll be checked and double-checked, and you know they'll work with medical writers all these kind of things. So, things tend to be reasonably polished by the time they reach me." (Participant 10).*

> *"I do see the appeal of author-written plain language summaries because the author's invested…The author knows the subject best and is not likely to misstate or less likely to… But the trade-off is the one we've discussed, which is, they also don't know how to talk about it." (Participant 16).*

2.2 Editors

In terms of editors' roles, perceptions were similarly varied. Some editors and members of their team took a proactive approach, intending to work with authors to improve PLSs. However, it was up to the individual editor how much time and effort they put into this area.

> *"I definitely have associate editors who are pretty good about going in and saying, 'Yeah, this doesn't make any sense. You need to clarify this', to authors, and there are others who don't necessarily pay that much attention to it." (Participant 8).*

> *"With regards of (sic) the resources we have and the benefits we might get out of these resources, so, for me also, that is not a priority. But I would not necessarily neither pay too much attention on what the content is if that could not be improved. And if that indeed is plain language, or if that is still like too scientific to be called plain language." (Participant 2).*

One participant noted that their journal had a team of "structural editors" who have an active role in PLS editing, but this was the exception rather than the norm amongst the participants we spoke with.

> *"So, we have a team of structural editors, and they find that they nearly always have to rewrite them quite substantially because the authors, you know, they provide us with one, but it's often, you know, not very well written, or is kind of is too technical. So, we, one of our team will rewrite it into a form that we think is kind of the most accessible." (Participant 2).*

2.3 Peer reviewers

PLSs are rarely considered a notable part of peer review, nor a priority for peer reviewers. The participants we spoke to felt that this is primarily due to a lack of formal processes to flag PLSs during peer review; PLSs are rarely included in peer review guidelines, and reviewers are not prompted to comment on them. When peer reviewers did comment on the PLS, most often, it was about the content rather than the language. For example, reviewers noted that PLSs might contain exaggerated or out-of-context findings rather than too much jargon, acronyms, abbreviations or complex language.

> *"Not really because it's not really a question that we're asking the reviewers." (Participant 3).*

Perceptions of peer-reviewers role in the implementation of PLSs varied between participants, with some agreeing that PLSs should be given more attention by reviewers and others believing that is not the function of peer review given that the "*the most important target or objective we have for this is* [a review of] *scientific content methods".*

> *"I completely understand that they would not spend too much energy on what the patient summary contains. And that is, yeah, fine." (Participant 2).*

2.4 Consumers

Some editors expressed support for consumer involvement in PLS co-design, acknowledging that it is "*a good thing that patients get more and more involved"* and that "*some will take a huge benefit out of it".* However, they noted that it was not for everyone. An additional common concern we heard from editors was that including PLSs could slow down the publication process. Participant 2 expressed the involvement of consumers in the production of PLSs because they might lack an understanding of the research process.

> *"What would be helpful indeed, like having a patient or a lay re-reading this part before publication. But then, I'm not really sure we would be able to find somebody who would provide that in a fruitful fashion. Because, yeah, either you're familiar with the scientific publication process...or you're not. And then you might probably slow down the entire publication process." (Participant 2).*

There was an acknowledgement that co-design with consumers needed to be done meaningfully or not at all. A few journals or publishing groups achieved this by establishing consumer advisory panels. At least one-panel member would review all PLSs and provide feedback according to guidelines for consumer reviewers. There was, however, disagreement about how to allocate PLSs to consumers. Some editors felt that, ideally, consumers should review summaries on topics in their area of expertise or for which they have lived experience. Others deliberately matched consumers with summaries outside their experience, believing consumers are more effective reviewers when unfamiliar with the subject.

> *"It needs to be 2 or 3 people, so they don't feel like they're just the token person in a group who's there just to tick a box. Then you have to have a strategy for how you involve them and all of that kind of thing… I think that I don't want to do it half-heartedly…So I think it's around not just sort of tacking them onto your kind of current processes and expecting them to get involved. But actually, you know, really meaningfully involving them in all the relevant parts of the processes." (Participant 3).*

Theme 3. A cautiously optimistic approach to support from artificial intelligence (AI)

Having noted that PLSs take time to write effectively and the skill level of authors will vary, many participants expressed enthusiasm for the potential of AI technology to generate PLSs. Here, AI was seen as an opportunity for authors who either lack the skill, time or interest to write a PLS to be able to produce one of better quality. Although believing AI to be useful, all recognised the need for a 'human-in-the-loop' to check the AI output as the accuracy varies.

3.1 A good starting point

There was widespread acknowledgment that PLSs require skills different from those needed for academic writing. This is where participants in our study saw AI as most beneficial to authors, reflecting on their challenges in writing PLSs. Helping authors make a start with a PLS was seen as a practical way of using AI, "*…even if it produced a 1st draft*". Generating infographics was seen as another positive potential use of AI. With the number of journals offering visual abstracts, editors favoured authors or journals themselves, potentially using AI to produce high-quality infographics as another way of communicating with a broader audience.

> *"I mean, I know people who are using AI. I know authors have told me they're using AI to generate infographics of their content. And again, you know, given how hard it is to, you know, develop nice infographics, I could see that that's actually possibly quite a useful tool, use of it ." (Participant 3).*

3.2 The responsible use of AI

While enthusiastic, nearly all editors recognised that there would always need to be a 'human in the loop' to check the output as the accuracy of AI varies. They felt that evidence providers are responsible for ensuring that information in PLSs is accurate and something readers can rely on. Some participants also felt that authors would need to declare the use of AI in producing PLSs, as they would for any other part of their manuscript. Most journals have a policy for reporting AI; however, it does not specify whether this applies to the main manuscript or all parts of the submission. Most participants agreed that AI use is in its infancy and AI policies will become more detailed in the future.

> *"Yeah, yeah, I think we're a long way off, a long way off. I wouldn't want to send something out without having checked very, very thoroughly that it was, you know, actually properly representing the review." (Participant 4).*

> *"I mean, obviously, there's always gonna have to be human intervention in it. But I don't think it's the kind of thing where it would be wrong to explore using it." (Participant 3).*

3.3 Does AI pose unforeseen risks?

A few participants commented on their concern about introducing AI to write PLSs before the consequences are fully understood by those in academia and publishing, including risks associated with putting data in an open system and how this might impact copyright. One participant pointed out that, like humans, AI systems have biases. This reinforces the notion in sub-theme 3.1 that a human should check all AI outputs for accuracy and to check for any biases in the data they provide.

> *"…which I think is a challenge, kind of if an author doesn't understand the consequences potentially of that, like putting their data in kind of an open AI system. But that's the same for anything, not just scientific data. So, there's definitely risks associated, and I think it will come with, again education of authors and them understanding how it works." (Participant 19).*

> *"Here's the rate-limiting step. Right, for you to use a large language model either to generate a plain language summary, or to generate a figure, you have to upload the paper to chat GPT or whatever machine AI machine that you want to use, and because our most of our papers are copyright, and that copyright is held by publisher X, they're not free, they're not free to access. Whereas if you put it out there on the Internet, in Chat GPT, it's free for everybody. And the license and my understanding is the copyright, once you've uploaded it is held by the large language model." (Participant 17).*

> *"The one thing that I would say we just need to be really careful about with AI is, we know, all these biases that we have. There are within the training programs for AI. We know that they, you know, they underrepresent, you know, certain populations. They underrepresent certain parts of the population as well. So, I think that using AI in a way that is kind of mindful is probably fine. But we do need to understand what its biases are." (Participant 3).*

Theme 4. Blind spots and broken loops

Editors told us that journals rarely receive feedback on the quality or usefulness of the PLSs they produce. This is because there is no process for this, and unsolicited feedback is seldom provided. This makes it difficult to know if they are reaching their target audience and whether there are ways in which they could deliver a more effective product. This is complicated by the broad nature of PLS readers and the varied audiences that journals strive to cater for with their PLSs.

4.1 Who is the actual target audience?

Editors had varying opinions about the target audience for their journal's PLSs. For some journals, this is based on the scope and topics covered by the journal. Although most editors agreed that their PLSs were aimed at a non-expert audience, views differed in the definition of 'non-expert'. Some editors understood this as being health practitioners, researchers from other fields, policymakers and journalists. In these instances, most editors did not think that the PLSs in their journals would be of interest to a general audience, i.e., the general public. This was mainly the case where the journal's scope was narrow, e.g., catering to a specific type or category of medical condition. Other editors considered anyone a potential reader of their journal's PLSs.

> *"The general public, that will include all the peoples, like even the clinicians, the patients like the others, health researchers who can understand the maybe the statistical terminologies or the research terminologies. So, if you say the general audience, general readers, or general public, so that's fine, maybe." (Participant 5).*

> *"One of the themes that came up with our discussion of plain, of plain language summaries was the need for some doctors from different disciplines to be able to understand the material as well." (Participant 11).*

The lack of clarity around the target audience sometimes made it challenging to decide on the appropriate label for PLSs, with participants reporting "*many endless discussions about what we should call this".* While most journals use the label 'plain language summary' to convey the purpose of the summary, others opted for more audience-oriented labels, such as 'Patient summary'.

> *"That's why we intentionally, indeed, selected the term patient summary, because it really targets the patient….to make sure that they understand that this part is for them and that they might get some plain language information." (Participant 2).*

4.2 Evaluation is difficult without readership data

A reported lack of data on the actual readership of PLSs further complicates the difficulty of pinpointing the audience of PLSs. Here, some participants acknowledged that there might be a difference between the target and the actual audience. This is complicated because most PLSs are attached to articles published open access. Unlike the subscription model, data on readership cannot be obtained from open-access journals. Editors we spoke with wanted to evaluate aspects of their journals' PLSs but were reluctant to do so without the evidence.

> *"Ultimately, our journals that publish these are open access, or if they are in a hybrid journal, then the plain language summary is always open access, but this makes it really difficult to track who is specifically reading them." (Participant 12).*
>
> *"I would love to have some more data on who is using them and how they're using them properly. And I would really love to be able to revisit the template and the guidance and say, 'Well, hang on! Is this working? Do you like this?', you know, because I think I think there are things that could be tweaked, and I would like to do that, but not without the evidence." (Participant 4).*

Theme 5. A 'one size fits all' approach doesn't work: the need for novelty

Participants had many ideas about creative strategies to make PLSs appealing and accessible to a more diverse audience. These strategies included the introduction of novel formats beyond text-based PLSs and using novel avenues to distribute PLSs.

5.1 Novel formats

Despite challenges pinpointing the audience of PLSs and a lack of data on actual readership, there was a general acknowledgement that novel approaches to PLSs are needed, particularly to improve accessibility for diverse audiences. We interviewed a few people with experience working with plain language summaries of publications (PLSPs) across more than one publishing group. Although a minority in our sample, these participants were enthusiastic about this as a more novel format for PLSs. While PLSPs serve a similar function to that of PLSs, notable differences make them more discoverable and freely accessible as they are not housed behind paywalls (Rosenberg et al., 2023). Also, at up to eight pages, they are considerably longer than PLSs, enabling more content to be included for the reader (Rosenberg et al., 2023). Some notable aspects of PLSPs participants pointed out were that they are a separate article category with their own DOI number. As such, they could be indexed by catalogues such as PubMed, Medline, and Google Scholar. As they noted, PLSPs tend to have multiple authors, including at least one person from the authorship team of the original manuscript, along with patients/carers or someone with relevant lived experience. Our participants also noted that PLSPs tend to be peer-reviewed by patients or consumers.

> *"Yeah, I think it's an article type that's here to stay. Now, there's, I think, for publishers that do this type of content already, and the more the merrier, really, because it's the whole purpose of it is to make research more accessible to people that need it." (Participant 19).*

> *"So, they (patients or consumers) generally peer review them just to make sure that the article sort of reflects the original publication. You know that they've not sort of cherry-picked any of the data or misrepresented any of the data, and that actually, it is written in the, in plain language in a way that they can understand… patient reviewers also have a lot of experience in reviewing these types of articles. They know what they should look like." (Participant 18).*

More commonly, editors viewed the provision of accessible research content in formats that were not text-based as a positive step and one that might increase the journal's readership. This discussion often centred around readership diversity and concerns that many people may struggle with text-based information written in English, recognising *"it's a huge barrier that is in the way science is disseminated".* This included, for example, people from a non-English speaking (NES) background and those with chronic medical conditions that can impact visual or auditory processing and cognitive functioning. The formats discussed were podcasts, infographics and video/visual summaries or abstracts.

> *"There's lots of different ways to think about what a PLS is. So, at the moment, I think we're mostly focusing on the text. And then this is the more infographic-type side of things. But I think there's a lot of potential in all sorts of different formats, whether that's audio or video, or, you know, more interactivity." (Participant 10).*

> *"We have a podcast…we are in Apple podcast, Spotify… And we're doing some interviews and so on. So, I think that nowadays there's a huge uptake in podcasts for*

> *information as well because people listen to it while [sic] commuted to work while cleaning their house." (Participant 6).*

However, once again, there was an acknowledgement that different formats require additional and specific resourcing to be successfully implemented and maintained at scale across a journal or publishing group.

> *"I would really like us to move to even having video summaries…it takes time to do them, and this is one of the things I learnt when I was at [journal X]. We had three very experienced editors, and we thought, how hard can these be to write? They're really hard to write. I estimate it took us; it could take anything from 3 to 5 hours to write one… they're not trivial to do." (Participant 3).*

5.2 Novel dissemination routes

The availability of articles and their PLSs varied between journals, depending on the publishing model, i.e., subscription, open access or hybrid. Most participants agreed that journals publishing open access should include PLSs as this aligns with the principle of making research widely available. There was no clear consensus about how best to deal with articles that were not published open access. The main issue raised by participants is that when articles are behind a paywall, so is the PLS. Members of the public and other potential readers cannot access them as they are not likely to have a subscription, nor would they be willing to pay a one-off fee. Housing the PLS in a separate part of the journal website that is searchable and accessible was not seen as a solution because people might want to read the article and the PLS.

> *"It would be interesting to see how they could access it, and it probably makes sense to have, like, the patient summary available outside of the open access or not open access wall. But then, I have doubts that somebody would be just happy with the let's say, five sentences. Probably they would like to look more into detail and get more information than just with this plain language summary, which I think is just a teaser*

> *and not necessarily the only information that should be getting out of an article. That is just too short, and I think not really helpful, I would expect." (Participant 2).*

Due to the popularity of health information on social media, we asked participants about their experience integrating social media and PLSs and whether this was initiated by the author or journal/publisher. Most stated that authors rarely seemed to share PLSs of their work on social media, although some noted that they didn't pay close attention. One person explained that this might reflect the article's funding source rather than the author's choice. A few participants pointed out that medical writers write many PLSs and PLSPs for articles with industry funding. In such cases, social media is not the preferred method of promoting an article PLS or PLSP.

> "One of the things that we have considered is like, how do we distribute these, the articles on social media. For example, you could imagine that perhaps a box with the summary in it might actually be quite useful, little social media tile, but don't do that routinely at this point." (*Participant 3*).

> *"There is a concern that people might see it as promotional if people were sharing it sort of far and widely, you know, so there may be a reluctance from authors to share it or from the company sponsors to share it." (Participant 3*).

One participant mentioned using a mixed approach of new and traditional media, i.e., newspaper, radio and television, as avenues for spreading health information through PLSs. This was seen as a way of reaching even more people.

> *"I think we would also need to think about having other media taking up the information, like if you would not only have your information inside of a scientific journal but maybe also like a normal newspaper or the Internet. I think that is where it becomes very helpful to get in this direction…the people being inside of a New York Times or whatever that they would be able to capture that information being, let's say, attracted by that information because they might not necessarily be super*

> *scientific either. But they might capture it and see, okay, that's interesting. And why not having an article or a paragraph on this information? And if you have indeed understandable information coming from our journal outside of our journal, then this might be something that you can achieve." (Participant 2).*

Three participants mentioned that they disseminate PLSs or PLSPs through their growing network of consumer support groups. Those who used this approach kept a spreadsheet of consumer groups and would match the topic of a new article to that of a consumer group and send them the associated PLS or PLSP. If they did not have any matched groups in their database, the team would conduct an online search and add relevant groups, growing their potential reach.

> *"It is a kind of more general method of accessing the content. And we know, we obviously share them with patient groups when they're published. So, it is going directly to groups to share if they want to. And patient groups, we know, have included them in their newsletters and in their own social media, and we publish on our social media, as well." (Participant 19).*

> *"What we do is we tend to make patient advocacy groups aware of them. And then they can choose to share it with their membership or not." (Participant 12).*

> *"Try where relevant to contact any relevant patient advocacy organisations. So, if they want to share content, then they can… it's letting people, the right people, know it's there." (Participant 10).*

Discussion

This qualitative study, which included 20 journal editors representing 23 journals and eight publishing companies, provided valuable insight into the perspectives of journal editors on the publication of PLSs. While most editors supported or invested in publishing PLSs, practical barriers to their implementation were consistently reported. These included barriers related to resourcing, organisational commitment from publishers, difficulties assessing PLS readership and reach, and a lack of clearly defined roles, commitment and relevant skills among authors, peer-reviewers and editors. The future of PLSs was considered important in adapting to emerging technologies such as AI, using innovative formats for PLSs to cater to a more diverse audience, and acknowledging some unexplored distribution channels, including consumer groups and social media.

The results of our study support and extend those of others related to PLSs, which have mainly ignored implementation issues. Similarly, Bároniková et al. (2024) conducted a quantitative study of journal editors. While in common with our study, they identified implementation barriers, including infrastructure challenges such as time, money and personnel, with mixed support for PLSs in peer review, there were some critical differences in results. For example, in Bároniková et al. (2024), 26% of journals stated that PLSs were not offered because they were irrelevant to journal content, whereas we rarely heard this sentiment in our interviews. Instead, the main reasons we were given for journals not offering PLSs were because the target audience was primarily medical professionals or that the decision was made to focus on making the manuscript abstract more accessible on the basis that many people do not read past the journal abstract. These noted differences between our study and Bároniková et al. (2024) could be due to the differing scope of journals in each study and the different data collection methodologies used in each study. Bároniková et al. (2024) conducted a largely quantitative survey distributed electronically, and our study consisted of one-on-one semi-structured qualitative interviews. Our study and Bároniková et al. (2024) found that the target audience for PLSs was mixed, mainly consisting of patients and patient groups, as well as medical practitioners and researchers. Bároniková et al. (2024) noted students as a familiar target audience of PLSs; however, few participants in our study did so. Support for PLS in peer review was mixed in Bároniková et al. (2024), which we also noted in our study.

Strengths and Limitations

This is the most comprehensive study on the decision-making process that governs the publication of PLSs, covering barriers, facilitators and attitudes of journal editors towards

PLSs. The sample included a diverse voice within health and medical journal publishing, including journal editors and those representing publishers or publishing groups. Also, we intentionally included editors associated with journals that did not publish PLSs and those for which PLSs were not mandatory. This provided us with rich interview data to fully answer the study's aims, and rigorous and reflexive qualitative analysis methods supported it. However, despite international recruitment, we did not have participants from journals based in Asia, South America or Africa. Coupled with the exclusion criteria of editors who did not speak English, we do not know if there are substantial differences in the perspectives, barriers or facilitators to the publication of PLSs in those geographical regions not represented.

Future directions

The qualitative findings from this study point to several directions for future research and practice. Firstly, there is a need for practical support to enable the generation and publication of more articles using PLSs. Many editors and publishers face a lack of resources such as time, money, and personnel, posing pragmatic limitations to the publication of PLSs. Based on discussions with participants, any solution will likely need publisher approval; however, investigating the degree to which some of the processes involved might be automated may be worth investigating. For example, our findings point to the potential of generative AI tools to develop the first draft of a PLS and relatively minor modifications to journal submission portals to better accommodate the inclusion and review of PLSs. Structured support through communication and monitoring systems is also needed to make the production and review of PLSs as easy and streamlined as possible. On a practical level, academic institutions could assist authors from all specialties of health and medicine by focusing on plain-language skills via training. Open-access publishing has made it easier for anyone to access scientific research. However, it has made it more difficult for journals to assess their impact, particularly the effect of the PLSs they publish. Future research could explore ways of evaluating PLSs to establish a more evidence-based approach to PLSs, including conducting reader surveys. Opportunities exist to explore the publication of PLSs in small, niche journals to determine if barriers to PLS publication and production differ based on journal size and focus. This would be of particular relevance to journals affiliated with patient groups, for whom PLSs would be a vital resource for members.

Conclusion

PLSs have the potential to engage people meaningfully with trustworthy research. While many individuals in health and medical publishing are enthusiastic about producing PLSs, several barriers exist in the publication and dissemination pipeline. Although PLSs have been used in health and medical publishing for several decades (Haughton & Machin, 2017), ongoing collaboration between all interest holders would help advance this field to benefit all involved. This could provide an opportunity for PLSs to play a greater role in disseminating evidence-based health information to a diverse audience.

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Statements and declarations

Declarations of conflicting interest

Karen M. Gainey, Kirsten J. McCaffery and Danielle M. Muscat have completed the International Committee of Medical Journal Editors (ICMJE) uniform disclosure form at http://www.icmje.org/coi_disclosure.pdf and declare no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous 3 years; and no other relationships or activities that could appear to have influenced the submitted work, with the exception of Health Literacy Solutions Pty Ltd, at which Kirsten McCaffrey and Danielle Muscat are directors. Kirsten McCaffery and Danielle Muscat are Editors of health and medical journals.

Ethical considerations

This study was approved by the low-risk ethics committee at the University of Sydney, Australia (approval number: HE001170).

Consent to participate

Consent was provided via a written consent form or response to a Qualtrics survey.

Consent for publication

Not applicable.

Funding statement

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Data availability statement

The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

Chapter 6. Discussion

Overview of the thesis

This thesis offers an exploration and critical examination of the capacity of PLSs to deliver health research to a diverse audience. The research covered by this thesis advances knowledge of PLSs, exposing gaps and opportunities related to their implementation and posing novel directions for research and practice to continue to advance the field. In a time when public trust in science and medicine may be wavering, we must provide the public with transparency in and access to medical research. As accessible explanations of medical research, PLSs have the potential to play a pivotal role in achieving this.

My thesis contains three published papers; one was submitted for publication and is currently under review. The first study (Chapter 2) is a scoping review (n=534 health and medical journals) of the author guidelines for writing PLSs from highly rated journals across ten non-communicable disease categories. This built on previous research (Duke, 2012; Haughton & Machin., 2017; Narayanan et al., 2018; Shailes, 2017; Stoll et al., 2022) by systematically analysing these guidelines according to pre-established criteria, including quantitative and qualitative data about elements in the instructions such as word count, structure and use of jargon, acronyms and abbreviations. This study was followed up with an environmental scan (Chapter 3), which compared published PLSs with the PLS author instructions from 26 of the 27 journals identified in Chapter 2, and a review of how closely the PLSs conformed to health literacy recommendations, including those related to readability. To better understand the results of Chapters 2 and 3 in a practical context, I next conducted two qualitative studies on the attitudes and perspectives of two cohorts of interest holders regarding PLSs: health consumers (Chapter 4) and journal editors (Chapter 5). Both studies involved semi-structured interviews and focus groups analysed using reflexive thematic analysis. The first, involving 19 people living with chronic medical conditions from six countries, explored what was most important to readers of PLSs in terms of content, design, structure and the label used. The second, with 20 editors representing 23 journals and eight publishers/publishing groups, examined the barriers and facilitators to the publication and distribution of PLSs.

Summary of principal findings

The series of studies outlined above offered key principal findings. First, Chapter 2 revealed the inconsistency in PLS author instructions between journals in content and level of detail and highlighted a lack of health literacy recommendations in these instructions from most health and medical journals. Specifically, after screening 534 journals, I identified only 27 (5.1%) with guidance for authors on how to write a PLS. In most cases (70%), a PLS was not mandatory for the journal, only an optional inclusion. There was inconsistency in the author instructions between journals regarding specific content and the level of detail. For example, the word count or length varied from 100-850 words, and not all journals included guidance on using jargon, abbreviations, and acronyms. Only one journal suggested the use of a readability tool. Next, Chapter 3 highlighted the discrepancy between author instructions for writing PLSs and published PLSs from health and medical journals. Most PLSs did not appear to be written according to the journal author instructions; only two journals (10%) achieved high (>80%) compliance, 13 journals (65%) achieved a medium level (51%–79%) of compliance and five achieved low or very low (≤30%) compliance (25%). The grade reading levels of the PLSs ranged from grade 10.2 to 21.2 with a mean of 15.8 and a median of 15.9, and the use of complex words ranged from 8.5% to 49.8%, indicating that most PLSs were written at high reading levels and contained a substantial proportion of complex words. Notwithstanding their limitations, these health literacy assessments show that most of the PLSs may be unsuitable for a non-expert audience.

Chapter 3 showcased the aspects of PLSs considered most important according to people who read and use them. From interview and focus group data, four themes were developed: (i) 'Accessing information in a competitive landscape of health information'; (ii) 'I really don't see the patient in this at all'; (iii) 'Co-design should be meaningful, not tokenistic'; and (iv) 'A way forward: Approach PLSs with creativity'. Reflecting on the overloaded modern information environment, participants highlighted the importance of PLS labels, the need for actionable content, and the recommendation to vary the reading level depending on audience needs. The results of this study suggest that PLSs produced with consumer input could elicit PLSs that better meet audience needs, focusing on information that is actionable, accessible, and written with helpful content that is detailed but still respectful of the reader. Chapter 4 offered a different but complementary editorial perspective, revealing the complexities of producing, publishing and disseminating PLSs. From the data of this second qualitative study, five themes were developed: (i) When good intentions clash with practical realities; (ii) Whose job is it anyway?; (iii) A cautiously optimistic approach to support from artificial intelligence; (iv) Blind spots and broken loops; (v) A 'One size fits all' approach doesn't work. Discussions with participants highlighted the differing approaches taken by journals to prioritising PLSs, often governed by barriers such as resource allocation and the need for standardisation within publishing groups. Many participants showed initiative to overcome barriers, often in their own time. All participants had a favourable view towards PLSs and expressed a willingness to improve systems at the journal or publishing level to improve how PLSs are produced and distributed.

When viewed in their entirety, the findings from my thesis demonstrate that more effort is needed to support the production and dissemination of PLSs for diverse audiences. These studies suggest that the field of PLSs, although growing in popularity, experiences a lack of structural support at multiple levels. Authors are disadvantaged by inconsistent and sparse author instructions to assist with writing PLSs, and editors face resource limitations and a lack of data on PLS use and uptake, which jeopardise the prioritisation of PLSs. These challenges result in processes that do not support consistent production of high-quality PLSs, with PLSs failing to meet consumer needs. Consumers must work against an overloaded information environment to locate PLSs that don't always meet their needs, with few known avenues to contribute meaningfully.

The findings from one journal emerged as noteworthy because this journal was represented in three of the four studies. Findings specific to this journal from each distinct study are summarised in Box 1 as an illustrative example of the multiple and cumulative barriers to PLS production and dissemination. This example spotlights the disconnect that can occur when implementation lags behind intention in publishing PLSs. It also underscores the utility of different data sources captured across this thesis and the varied methodologies; Study 4 was able to usefully illuminate some of the challenges underpinning findings about the detail of author instructions and compliance.

Box 1. Example of one journal across three studies

Key findings

In this example, author instructions for PLSs were minimal, compliance among authors was low, and the interview with the journal editor indicated little practice support for PLS production from the journal management despite in-principle support.

- Study 1 – Scoping review
  - Minimally detailed author instructions, including only length and structure.
  - Author instructions included having 2-3 short sentences and suggesting "describe your findings to a non-medical audience".

- Study 2 – Compliance study
  - "Very low" compliance rating, with zero compliance across all PLSs rated (n=3).
  - "Poor" rating for readability with a mean grade reading level of 16.7 from all 3 PLSs.
  - Poor rating for use of complex language with a mean of 32.6% complex words from all 3 PLSs.

- Study 4 – Qualitative study
  - The Editor-in-Chief reported a positive attitude towards PLSs, considering them an important feature of the journal.
  - The relationship between the journal and patients was valued, with patient-centred management being a future focus.
  - There was an acknowledgement that no one at the journal specifically checks PLSs to determine if they comply with journal PLS author instructions.
  - Lack of clarity about roles and responsibilities; PLS review considered a possible task for the copy editor.

Strengths and limitations of the thesis

As noted in the preceding chapters, there are strengths and limitations for each of the research studies included in this thesis. A primary strength of this thesis is the cohesive nature of the studies included and the logical progression of the research questions, which deliberately and systematically seek to address evidence gaps related to the implementation and use of PLSs. Collectively, these studies represent a substantial advance in the understanding of PLSs and their role as a health communication device, both by their end users and publishers, advancing the field through a more wholistic, implementation-focussed approach as opposed to focusing on, for example, discrete formatting and linguistic considerations of PLSs which dominate the published literature (Anderson et al., 2021; Bredbenner & Simon, 2019; Carvalho et al., 2019; Lang et al., 2025; Pfershy-Wenzig et al., 2016; Stricker et al., 2020; Wen & Yi 2023: 2024).

In terms of study methodology, this thesis includes a scoping review, an environmental scan and two qualitative studies utilising reflexive thematic analysis. For the first two studies (Chapters 2 and 3), the methodologies were chosen in preference to a systematic review as they were better suited to answer the research questions. For Chapter 2, a scoping review was chosen because they are ideal for identifying and mapping available data, particularly when used to identify specific concept characteristics, as was the case with the elements in the journal author instructions for PLSs (Munn et al., 2018). For Chapter 3, an environmental scan was chosen because this methodological approach has been used widely in healthcare to assess strengths and weaknesses and guide quality improvement strategies (Charlton et al., 2021). I adapted this approach to apply it to academic research, developing bespoke data collection and analysis methods. Uniquely, the scoping review and environmental scan projects analysed data and categorised it as grey literature rather than scholarly research publications. To aid with analysis and reporting, I drew on established guidelines to ensure rigour in study design and reporting, specifically consulting resources developed by Tricco et al. (2018), which detailed the steps to take when conducting and reporting a scoping review. Due to the unconventional nature of Chapter 3 (i.e., environmental scan and compliance study) and the lack of reporting guidelines available in the EQUATOR network, I developed novel data collection, synthesis and reporting strategies from the outset. In Chapters 4 and

5, an in-depth qualitative approach offered rich, nuanced insights into the meanings individuals ascribe to their experiences with PLSs, privileging depth over breadth. Drawing on Braun and Clarke's reflexive thematic analysis (Braun & Clarke, 2006: 2019), such an approach emphasises researcher subjectivity as a resource with an appreciation for knowledge development through iterative engagement with the data, ideal for phenomenological research. This approach enabled the development of latent themes and the interrogation of underlying assumptions within discourse. When reporting the qualitative studies to ensure rigour, I used the list of 20 evaluation questions developed by Braun & Clarke (2021, Table 1) to guide best practice in thematic analysis for Chapter 4 and the Standards for Reporting Qualitative Research (SRQR) in Chapter 5 (O'Brien et al., 2014).

While there are key methodological strengths, it is important to acknowledge the potential limitations of this thesis in representing the full spectrum of perspectives relevant to the development and implementation of PLSs. While concerted efforts were made to include diverse interest holder voices, including end-users and editors, certain viewpoints remain underrepresented, including those of researchers and PLS authors. In addition, the views of health consumers who have not previously engaged with PLSs were not systematically captured, with Chapter 4 including only two such participants. As such, this thesis cannot account for the informational needs, expectations, and barriers to using PLSs amongst this cohort. To capture multiple viewpoints from journal editors about PLSs, the decision was made to target editors from journals that did not publish PLSs and those that did. Despite including four editors from such journals, such perspectives remain insufficiently explored. Editors from these journals may hold critical insights into the structural, editorial, or epistemological barriers to PLS adoption that could enrich understanding and guide better implementation. Moreover, despite international recruitment, viewpoints underrepresented in both qualitative studies are those from PLS readers and journal editors located in Asia, South America or Africa and, more generally, participants who did not speak English. It is possible that PLS readers and editors from these geographical regions had different experiences with PLSs that might have contributed distinctive perspectives, enriching the study findings. These omissions underscore the need for continued inquiry that engages a broader range of voices, particularly those positioned at the margins of current PLS practices, to ensure a more comprehensive and inclusive account of their design, dissemination, and impact.

Finally, the focus on text-based PLSs only could be considered a limitation of the thesis and the studies contained within it – particularly Chapters 2 and 3. This decision was deliberate and was based on the context within which PLSs were published at the commencement of this thesis; at the time, non-text-based PLSs were still new and not as widely offered by journals as they are today. While text-based PLSs are still the most common format for PLSs (Gunn, 2024), enhanced formats are available to assist researchers in reaching a wider audience, either as standalone pieces or in combination with text-based PLSs. Some newer examples of enhanced content, also referred to as "publication extenders" (Pal et al., 2024), include infographics, podcasts, video abstracts and plain language summaries of publications (PLSPs).

Implications and future directions

Directions for future research and practice stemming from this thesis

The findings from this thesis's studies pinpoint critical points in the production and publication of PLSs where processes could evolve to serve all parties better. For example, there may be opportunities to make the submission process simpler and more efficient for both researchers and editors. Adding a field in the submission portal with a word limit (if required) and PLS author instructions available in a pop-up box next to the PLS field, for example, could increase the visibility of PLSs and subsequent inclusion and compliance. Discussion with editors, reported in Chapter 5, suggested this initiative was feasible. Awareness campaigns and skills training may also support PLS development and evaluation. These initiatives should be available and tailored to various interest holders, including authors, editors, copyeditors and peer reviewers. Finally, perhaps rather than only seeing the PLS as having value if a journal publishes it, authors could see PLSs as a promotional tool for their work by sharing it on social media. If authors track and share the positive impact of sharing their work via PLSs on social media (e.g., increased engagement), this idea may gain traction over time.

While replication studies are unfortunately undervalued in biomedical research (Vachon et al., 2021), it would be valuable for the compliance study of this thesis to be replicated serially over time to add to the knowledge base and explore changes in compliance as research and practice evolve in this area. Follow-up studies could also examine reasons for the discrepancy in compliance between journals and the high usage of jargon and complex language recorded in the PLSs analysed. While there is now extensive research observing the high-grade reading levels of PLSs due to the use of jargon and complex language (Anderson et al., 2021; Carvalho et al., 2019; Lang et al., 2025; Stricker et al., 2020; Wen & Yi, 2023: 2024) little has been done to understand reasons for this.

Finally, to build on the results from Chapters 4 and 5 of this thesis, future research with those whose voices were not captured within this thesis might provide valuable insights and close knowledge gaps. For example, a qualitative study comprising semi-structured interviews with health and medical researchers could aim to uncover answers to some of the questions and issues raised by these previous studies, such as:

- views about PLS author instructions, whether they use them and factors that influence that decision
- what might help facilitate increased submission of PLSs and the usage of PLS author instructions?
- factors that influence their decision whether or not to submit a PLS when it is not mandatory
- views about and experience with the use of artificial intelligence tools to produce PLSs
- avenues used by researchers for the dissemination of their PLSs and what factors influence these choices

The experience and perspectives of researchers about PLSs have been largely unexplored. Dormer and colleagues (2022) developed a 'How-to" guide for developing PLSs after consultation with many stakeholders, including several academic researchers. The next step for the guide is evaluating impact and usability, ideally with an organisation willing to pilot the guide (Dormer et al., 2022). This and the aforementioned qualitative study(s) could provide valuable insights into how researchers view PLSs as part of their academic work.

Practice shifts in plain language summary development and dissemination

Beyond the findings of this thesis specifically, there have been shifts towards developing more comprehensive guidelines for writing PLSs. To maintain good practice in evidence synthesis, the Cochrane Library Editorial Board, for example, approved new guidance and a template for writing plain language summaries of Cochrane reviews (Cumpston et al., 2024). The guidance replaces the previous set of standards, the Plain Language Expectations for Authors of Cochrane Summaries ('PLEACS'). The revised guidelines and template result from the Cochrane Plain language summary project that ran between May 2020 and May 2021 involved extensive work from plain language experts and feedback from project volunteers. Released in early 2022, this revised version was accessed in data collection for Chapter 2, helping ensure that the study of PLS author instructions contained the most current information available. The revision process for the development of Cochrane's new guidance offers a transferable model that other journals and/or publishing companies can replicate to ensure that their PLS instructions are fit for purpose. Ongoing research exploring compliance with these new guidelines is needed. It can be directly compared to previous research, which found that, of the 1738 Cochrane PLSs analysed, there was a high degree of heterogeneity, with no PLS achieving full compliance with the original PLEACS standards (Kadic et al., 2016).

There have also been shifts towards greater standardisation of PLSs, which go beyond single journals or publishing companies. Open Pharma suggest that their criteria for PLSs should serve as the minimum standard across journals (Rosenberg et al., 2021). These recommendations take account of the PLS audience by considering aspects such as discoverability (e.g. indexing on directories such as PubMed and discoverable through search engines) and accessibility (e.g. made available free of charge and considerations for people whose primary language isn't English) (Rosenberg et al., 2021).

In a similar vein, Griffiths et al. (2022) sought to clarify the various labels used for PLSs to move towards standardisation of these terms across the pharmaceutical and publishing industries, now adopted in the Good Lay Summary Practice Guide (Griffiths et al., 2022). With the field of PLSs expanding, now is an opportune time to continue the momentum towards standardising author guidelines and terminology across health and medical publishing. This should be done with an appreciation that a flexible approach to producing PLSs is still required and an underpinning evaluation framework that allows for ongoing success monitoring. This could be informed by established frameworks such as RE-AIM, which focuses on reach, effectiveness, adoption, implementation, and maintenance outcomes (Holtrop et al., 2021).

Making plain language summaries more discoverable

Health information needs to be trustworthy, easy to understand, and available and easily accessible. The findings of this thesis suggest this is not always the case for PLSs. To make PLSs more discoverable, in early 2019, PubMed introduced a new function whereby journal publishers can tag PLSs with the XML tag 'plain-language-summary' in the Other Abstract field (Collins, 2019). This will allow the PLSs to be indexed on PubMed, where they are freely available to millions of users daily (Rosenberg et al., 2023b). Rosenberg and colleagues (2023a) measured the prevalence of the XML tag in PubMed records to determine the uptake by journal publishers. After analysing 31,817,472 PubMed records, they found that only 3217 (0.01%) had an XML tag 'plain language summary' in the Other Abstract field, with approximately half of these (1644, 51%) being published in 2021 (Rosenberg et al., 2023a). Of these 3217 records, 470 (14.6%) were incorrectly tagged (Rosenberg et al., 2023a). Although introduced over five years ago, the low adoption rate of this metatag may be due to a lack of awareness or understanding by journal publishers about how to use it correctly. Considering that half of the tagged records were published in 2021, it is possible that a future analysis would indicate a higher rate of adoption.

In a parallel attempt to make research more accessible, a free platform is also being currently developed, temporarily referred to as 'The PLS Finder' (Brooke, 2025). This website will be free to access and index PLSs of research articles, with search and filtering capabilities that will enable PLSs to be easily located (Brooke, 2025). The development of this website is a multi-publisher collaboration, which includes Becaris Publishing, SAGE and Taylor & Francis Group, in partnership with the Patient Focused Medicine organisation, Patient Engagement Synapse and The Synergist (Brooke, 2025). Once established, an evaluation of the impact of this website could help provide relevant and valuable data on public usage and preferences for PLSs. It would be beneficial to measure the number of PLSs searched, opened and downloaded from the site and determine if there are demographic patterns. For example, noting whether there are specific disease categories that are more frequently searched, age groups or people from specific geographical locations that access the PLSs more frequently. This data could help inform and direct future research in the areas of health communication and health literacy.

With a similar goal to enhancing accessibility, Plain Language Summaries of Publications (PLSPs) is a type of enhanced format first introduced by Future Science Group in 2020 (Rosenberg et al., 2023b). They serve a similar function to that of PLSs; however, notable differences make them more discoverable and freely accessible as they are not housed behind paywalls (Rosenberg et al., 2023b). As a separate article category with their own DOI number, PLSPs can be indexed by catalogues such as PubMed, Medline and Google Scholar (Rosenberg et al., 2023b). While these collective efforts represent essential steps towards enhanced accessibility of PLSs, ongoing research and evaluation are needed to understand their impact and support ongoing development efforts (Rosenberg et al., 2023b).

Publication extenders: beyond text-based plain language summaries

Offered by many journals to cater to PLS readers' diverse needs, enhanced content or "publication extenders" (Pal et al., 2024) include infographics, podcasts and video abstracts. However, research comparing different formats has garnered varying results. To assess the relative effectiveness and reader preference for text-based and non-text-based PLS formats, for example, Bredbenner and Simon (2019) conducted a survey of 538 participants, comprising 60% (N=323) with a science-based profession and 40% (N=215) without a science-based profession. The study involved a comparison of PLSs, scientific abstracts (text-based), video and graphical abstracts (Bredbenner & Simon, 2019). Video abstracts and PLSs led to the highest degree of comprehension, understanding and enjoyment (Bredbenner & Simon, 2019). A 2022 cross-sectional survey study of 167 patients or caregivers (Silvagnoli et al., 2022) similarly explored preferences for PLS format, comprising three text-only summaries (written with high, medium, and low complexity) and one graphical summary (i.e. infographic), finding that the graphical summary was the most popular format overall. In contrast, a survey of 188 healthcare professionals by Hadland and colleagues (2025) found that the most common format was text-based PLSs (83%), followed by graphical summaries/infographics (52%) (Hadland et al., 2025). Participants also rated text-based PLSs as the most valuable (78%), closely followed by graphical summaries/infographics (71%) (Hadland et al., 2025). Such varied findings reinforce the need for ongoing comparative evaluations of emerging formats. Continued reflections on what is within and beyond the scope of PLSs are also necessary.

The changing landscape of plain language summaries in research and practice

Since beginning the work for this thesis, the field of PLSs has grown, with increasing publications and new research directions. In 2025 alone, for example, burgeoning research has assessed the capability of generative artificial intelligence (AI), including large language models, in developing PLSs (e.g., Pavičić et al., 2025; Schmitz, 2023; Shaib et al., 2023). All authors came to similar conclusions, i.e., that the potential value of incorporating AI technology in the production of PLSs would benefit the field and that human oversight was vital to ensure quality control was maintained. This is not dissimilar to the findings of this thesis; editors in Chapter 5 openly discussed their experiences and views on the use of AI to produce PLSs. Most agreed that not only is there a place for AI in health and medical publishing and PLS development, but that researchers were already using AI to varying degrees. They, too, acknowledged that human oversight would be necessary to ensure the end product was suitable for publication. The health and medical publishing industry has responded to the rising popularity of AI with the introduction of policies by journal publishers to guide its use (e.g., PLOS One, 2025; SAGE, 2025; Taylor & Francis, 2025). However, none to date have been specific to the development of PLSs. In addition, given the findings of this thesis that researchers do not always adhere to journal guidelines or instructions, now could be an ideal time for journals to devote resources to develop more comprehensive governance systems for compliance of PLSs to author instructions, AI use and disclosure.

Challenges defining the audience for plain language summaries

At a fundamental level, my thesis highlights the challenge facing researchers and journal publishers when understanding the target audience for PLSs. Chapters 4 and Chapter 5 in this thesis, as well as other sources (Barnfield et al., 2017; Riganti & McKinnon, 2023; Rosenberg et al., 2023), have identified that the audience for PLSs is difficult to characterise due to its diverse nature and lack of data about the actual readership of PLSs, with possible discrepancies between the actual and presumed readership. The National Institute for Health and Care Research (NIHR) suggests the most widely accepted definition of a PLS in their guidance document, which states that they are "a clear, brief overview of research. It should be written clearly and simply, without jargon and with an explanation of technical terms. The summary needs to stand alone and be understood without further information" (NIHR, Plain English summaries, 2021). This guidance highlights two essential aspects of PLSs: first, they are summaries of research, and second, they are aimed at non-scientific or non-expert audiences. Of note, this definition does not specify 'the general public' as the audience for PLSs.

This current definition of a PLS poses a challenge for researchers to know how to write their PLS, for consumers to review correctly, and for editors to understand the most appropriate dissemination routes and review methods. Although accurate, it lacks sufficient detail that would prevent assumptions. A more nuanced definition would be more useful. Strategies to capture data on PLS readership are also urgently needed but not likely to be implemented as they are resource-heavy regarding time and personnel. Indirect methods made available through emerging formats such as PLSPs could provide helpful information and help track the impact of PLSs. These include monitoring changes in the number of citations, downloads and social media engagement. Once captured, this data should be shared to inform evolving definitions.

Conclusion

Looking back only a few years in the field of PLSs, several approaches previously thought of as just concepts or ideas are now becoming commonplace. Incorporating technology, these approaches add innovation to the production, publication, and dissemination of PLSs, prompting the thought that perhaps the future of PLSs is already here. Increasingly, the publishing industry seems committed to providing health research to all by building on the concept of PLSs, incorporating innovation and emerging technologies, seeking and testing solutions and embedding those solutions within principles of health literacy. However, the barriers to implementation identified in this thesis are real and ongoing. PLSs have the potential to meaningfully engage people with trustworthy research, playing an essential role in the oftentimes confusing landscape of health information, but only if researchers are structurally enabled to write and distribute them. Now is the time to unlock their real value and potential through ongoing research, continued critical examination and openness to innovation and change.

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Appendices

In this section, I have included the following information, arranged according to thesis chapter:

- Ethics approval letters
- Supplementary information included with the published (or submitted) manuscript

Appendix A (i)

Data screening

Nº	Journal Title by Category	Publish PLS or similar [1]	Include	Audience	Publisher	Label	Who Writes	Mandatory or Optional
	Medicine, General & Internal N=50							
1	New England Journal Of Medicine	0 *	0		Massachusetts Medical Society			
2	Lancet	0	0		Elsevier			
3	JAMA-Journal Of The American Medical Association	1 **	0	Not specified	JAMA Network	Key Points		
4	Nature Reviews Disease Primers	0	0		Springer Nature			
5	BMJ-British Medical Journal	1	0	Not specified	BMJ Publishing Group	Summary Box		
6	Annals Of Internal Medicine	0	0		American College of Physicians			
7	Lancet Digital Health	0	0		Elsevier			
8	JAMA Internal Medicine	1	0	Not specified	JAMA Network	Key Points		
9	Journal Of Cachexia Sarcopenia And Muscle	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
10	PLOS Medicine	0	0		PLOS			
11	Cochrane Database Of Systematic Reviews	1	1		Wiley	Plain language summary		M
12	Journal Of Internal Medicine	0	0		Wiley			

13	BMC Medicine	0	0		Springer Nature			
14	Journal Of Travel Medicine	0	0		Oxford University Press			
15	JAMA Network Open	1	0	Not specified	JAMA Network	Key Points		
16	Canadian Medical Association Journal	0	0		CMAJ Group			
17	Medical Journal Of Australia	0	0		Australian Medical Association			
18	Mayo Clinic Proceedings	0	0		Elsevier			
19	Amyloid-Journal Of Protein Folding Disorders	0	0		Taylor & Francis			
20	Translational Research	0	0		Elsevier			
21	Deutsches Arzteblatt International	NA	NA					
22	Medical Clinics Of North America	1	0	Not specified	Elsevier	Key Points		
23	British Journal Of General Practice	1	0	Clinicians	Royal College of General Practitioners	How this fits in		
24	Journal Of The Royal Society Of Medicine	0	0		SAGE			
25	Panminerva Medica	NA	NA					
26	Annals Of Family Medicine	0	0		Annals of Family Medicine			
27	Journal Of General Internal Medicine	0	0		Springer Nature			
28	Frontiers In Medicine	1	0		Frontiers Media	Contribution to the Field		

29	American Journal Of Preventive Medicine	0	0		Elsevier			
30	American Journal Of Medicine	1	0	Colleagues	Elsevier	Highlights		
31	Journal Of Personalized Medicine	0	0		MDPI			
32	Minerva Medica	NA	NA					
33	Palliative Medicine	1	0	Not specified	SAGE	Key Statements		
34	Annals Of Medicine	0	0		Taylor & Francis			
35	European Journal Of Clinical Investigation	0	0		Wiley			
36	American Journal Of Chinese Medicine	0	0		World Scientific Publishing			
37	European Journal Of Internal Medicine	1	0	Not specified	Elsevier	Highlights		
38	British Medical Bulletin	0	0		Oxford University Press			
39	Journal Of Clinical Medicine	0	0		MDPI			
40	Preventive Medicine	1	0	Not specified	Elsevier	Highlights		
41	Postgraduate Medicine	1	1	Patients, caregivers	Taylor & Francis	Plain language summary		O
42	Disease-A-Month	0	0		Elsevier			
43	Pain Medicine	0	0		Oxford University Press			
44	International Journal Of Medical Sciences	0	0		Ivyspring International			

45	Diagnostics	0	0		MDPI			
46	Journal Of Urban Health-Bulletin Of The New York Academy Of Medicine	0	0		Springer Nature			
47	Journal Of Pain And Symptom Management	0	0		Elsevier			
48	Journal Of Translational Internal Medicine	0	0		Sciendo			
49	Internal And Emergency Medicine	0	0		Springer Nature			
50	Military Medical Research	0	0		Springer Nature			
	Cardiac and cardiovascular systems N=50							
1	Nature Reviews Cardiology	0	0		Springer Nature			
2	European Heart Journal	1	0	Not specified	Oxford Academic	Translational Perspective & One-sentence Summary		
3	Circulation	0	0		American Heart Association			
4	Journal Of The American College Of Cardiology	1	0	Not specified	American College of Cardiology Foundation	Clinical Perspectives		
5	Circulation Research	0	0		American Heart Association			
6	Basic Research In Cardiology	0	0		Springer Nature			
7	European Journal Of Heart Failure	1	0	Lay audience	Wiley	Lay summary	Outsourced	O
8	JACC-Cardiovascular Imaging	1	1	General public	Elsevier	Lay summary	Author	O

9	JAMA Cardiology	1	0	Not specified	JAMA Network	Key Points		
10	JACC-Heart Failure	0	0		American College of Cardiology Foundation			
11	JACC-Cardiovascular Interventions	1	0		Elsevier		Outsourced	O
12	Cardiovascular Research	0	0		Oxford University Press			
13	Journal Of Heart And Lung Transplantation	0	0		Elsevier			
14	Cardiovascular Diabetology	0	0		Springer Nature			
15	Circulation-Heart Failure	0	0		American Heart Association			
16	JACC-Basic To Translational Science	0	0		Elsevier			
17	Progress In Cardiovascular Diseases	0	0		Elsevier			
18	European Journal Of Preventive Cardiology	0	0		European Society of Cardiology			
19	Circulation-Cardiovascular Imaging	0	0		American Heart Association			
20	European Heart Journal-Cardiovascular Imaging	0	0		Oxford University Press			
21	Trends In Cardiovascular Medicine	0	0		Elsevier			
22	European Heart Journal-Cardiovascular Pharmacotherapy	0	0		Oxford University Press			
23	Circulation-Arrhythmia And Electrophysiology	0	0		American Heart Association			

24	Circulation-Cardiovascular Interventions	0	0		American Heart Association			
25	Eurointervention	0	0		Journal of EuroPCR and the European Association of Percutaneous Cardiovascular Interventions			
26	JACC-Clinical Electrophysiology	0	0		American College of Cardiology Foundation			
27	Heart Rhythm	0	0		Elsevier			
28	JACC: Cardiooncology	0	0		American College of Cardiology Foundation			
29	Circulation-Genomic And Precision Medicine	0	0		American Heart Association			
30	Frontiers In Cardiovascular Medicine	0	0		Frontiers Media			
31	Heart	0	0		BMJ Publishing Group			
32	Journal Of Nuclear Cardiology	0	0		Springer Nature			
33	Circulation-Cardiovascular Quality And Outcomes	0	0		American Heart Association			
34	Journal Of Cardiac Failure	1	1	Patients	Elsevier	Lay Summary	Author	M
35	Journal Of The American Heart Association	0	0		American Heart Association			
36	Clinical Research In Cardiology	0	0		Springer Nature			

37	Journal Of Cardiovascular Magnetic Resonance	0	0		Springer Nature			
38	Journal Of The American Society Of Echocardiography	0	0		Elsevier			
39	Canadian Journal Of Cardiology	0	0		Elsevier			
40	Europace	1	0		Oxford University Press	What's New		
41	Journal Of Thoracic And Cardiovascular Surgery	0	0		Elsevier			
42	Current Problems In Cardiology	0	0		Elsevier			
43	Atherosclerosis	1	0	Not specified	Elsevier	Highlights		
44	Journal Of Molecular And Cellular Cardiology	1	0	Not specified	Elsevier	Highlights		
45	Revista Espanola De Cardiologia	1	0	Not specified	Elsevier	Key points		
46	American Heart Journal	1	0	Not specified	Elsevier	Highlights		
47	American Journal Of Physiology-Heart And Circulatory Physiology	0	0		American Physiological Society			
48	European Heart Journal-Acute Cardiovascular Care	0	0		Oxford University Press			
49	ESC Heart Failure	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
50	European Heart Journal-Quality Of Care And Clinical Outcomes	0	0		Oxford University Press			
	Oncology N=50							

1	CA-A Cancer Journal For Clinicians	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
2	Nature Reviews Clinical Oncology	0	0		Springer Nature			
3	Nature Reviews Cancer	0	0		Springer Nature			
4	Journal Of Clinical Oncology	0	0		American Society of Clinical Oncology			
5	Lancet Oncology	0	0		Elsevier			
6	Cancer Discovery	0	0		American Association for Cancer Research.			
7	Annals Of Oncology	0	0		Elsevier			
8	JAMA Oncology	1	0	Not specified	JAMA Network	Key Points		
9	Cancer Cell	0	0		Elsevier			
10	Molecular Cancer	0	0		Springer Nature			
11	Journal Of Hematology & Oncology	0	0		Springer Nature			
12	Seminars In Cancer Biology	0	0		Elsevier			
13	Journal Of Thoracic Oncology	0	0		Elsevier			
14	Trends In Cancer	0	0		Elsevier			
15	Journal For Immunotherapy Of Cancer	0	0		BMJ Publishing Group			
16	JNCI-Journal Of The National Cancer Institute	0	0		Oxford University Press			

17	Cancer Research	0	0		American Association for Cancer Research.			
18	Clinical Cancer Research	0	0		American Association for Cancer Research.			
19	Neuro-Oncology	1	0	Not specified	Oxford University Press	Key points		
20	Cancer Treatment Reviews	1	0	Not specified	Elsevier	Highlights		
21	Journal Of The National Comprehensive Cancer Network	0	0		National Comprehensive Cancer Network			
22	Liver Cancer	0	0		Karger International			
23	Leukemia	0	0		Springer Nature			
24	Clinical And Translational Medicine	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
25	Journal Of Experimental & Clinical Cancer Research	0	0		Wiley			
26	Cancer Immunology Research	0	0		American Association for Cancer Research.			
27	Blood Cancer Journal	0	0		Springer Nature			
28	Biochimica Et Biophysica Acta-Reviews On Cancer	1	0	Not specified	Elsevier	Highlights		
29	Cancer Communications	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
30	Oncogene	0	0		Springer Nature			
31	Annual Review Of Cancer Biology-Series	1	0	Not specified	Annual Reviews	Summary points		

32	Cancer And Metastasis Reviews	0	0		Springer Nature			
33	European Journal Of Cancer	0	0		Elsevier			
34	Cancer Letters	1	0	Not specified	Elsevier	Highlights		
35	Npj Precision Oncology	0	0		Springer Nature			
36	Therapeutic Advances In Medical Oncology	0	0		SAGE			
37	Oncoimmunology	0	0		Taylor & Francis			
38	Journal Of Pathology	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
39	British Journal Of Cancer	0	0		Springer Nature			
40	Oncogenesis	0	0		Springer Nature			
41	European Urology Oncology	1	1	Non-medical	Elsevier	Patient Summary	Author	M
42	International Journal Of Cancer	0	0		Wiley			
43	Gastric Cancer	0	0		Springer Nature			
44	Molecular Therapy-Oncolytics	0	0		Elsevier			
45	International Journal Of Radiation Oncology Biology Physics	0	0		Elsevier			
46	Cancer Immunology Immunotherapy	0	0		Springer Nature			
47	Npj Breast Cancer	0	0		Springer Nature			
48	Cancer	1	1	Those outside the scientific community	Wiley	Lay Summary	Author	O

49	Cellular Oncology	0	0		Springer Nature			
50	Cancer Science	1	0	Lay audience	Wiley	Lay Summary	Outsourced	O
	Rheumatology N=34							
1	Nature Reviews Rheumatology	0	0		Springer Nature			
2	Annals Of The Rheumatic Diseases	1	0	Not specified	BMJ Publishing Group	Key messages		
3	Arthritis & Rheumatology	0	0		Wiley			
4	Lancet Rheumatology	0	0		Elsevier			
5	Rheumatology	0	0		Oxford University Press			
6	Osteoarthritis And Cartilage	1	1	Lay audience	Elsevier	Plain language summary	Author	O
7	Seminars In Arthritis And Rheumatism	1	0	Not specified	Elsevier	Highlights		
8	Therapeutic Advances In Musculoskeletal Disease	1	1	General public	SAGE	Plain language summary	Author	O
9	Arthritis Research & Therapy	0	0		Springer Nature			
10	RMD Open	0	0		BMJ Publishing Group			
11	Current Opinion In Rheumatology	1	0	Not specified	Wolters Kluwer Health	Key points		
12	Joint Bone Spine	1	0	Not specified	Elsevier	Highlights		
13	Arthritis Care & Research	0	0		Wiley			
14	Journal Of Rheumatology	0	0		The Journal of Rheumatology			
15	Current Rheumatology Reports	0	0		Springer Nature			

16	Clinical And Experimental Rheumatology	NA	NA					
17	Lupus Science & Medicine	1	0	Not specified	BMJ Publishing Group	Key messages		
18	Best Practice & Research In Clinical Rheumatology	1	0	Not specified	Elsevier	Highlights		
19	Scandinavian Journal Of Rheumatology	0	0		Taylor & Francis			
20	JCR-Journal Of Clinical Rheumatology	1	0	Wider community	Wolters Kluwer Health	Plain language summary	Outsourced	O
21	Rheumatology And Therapy	1	1	Members of the public	Springer Nature	Plain language summary	Author	O
22	Pediatric Rheumatology	0	0		Springer Nature			
23	Modern Rheumatology	0	0		Oxford University Press			
24	Clinical Rheumatology	0	0		Springer Nature			
25	Lupus	0	0		SAGE			
26	Rheumatic Disease Clinics Of North America	0	0		Elsevier			
27	Rheumatology International	0	0		Springer Nature			
28	International Journal Of Rheumatic Diseases	0	0		Wiley			
29	BMC Musculoskeletal Disorders	0	0		Springer Nature			
30	Advances In Rheumatology	0	0		Springer Nature			

31	Archives Of Rheumatology	0	0		Turkish League Against Rheumatism			
32	Zeitschrift Fur Rheumatologie		NA					
33	Acta Reumatologica Portuguesa		NA					
34	Aktuelle Rheumatologie		NA					
	Psychology N=50							
1	Annual Review Of Psychology	0	0		Annual Reviews			
2	Annual Review Of Clinical Psychology	0	0		Annual Reviews			
3	Psychological Bulletin	0	0		American Psychological Association			
4	Psychotherapy And Psychosomatics	0	0		Karger			
5	Journal Of Child Psychology And Psychiatry	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
6	Psychological Review	0	0		American Psychological Association			
7	Psychological Medicine	0	0		Cambridge University Press			
8	Depression And Anxiety	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
9	International Journal Of Eating Disorders	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
10	Psychology Of Sport And Exercise	1	0	Not specified	Elsevier	Highlights		
11	Psychosomatic Medicine	0	0		American Psychomatic Society			

12	Health Psychology	0	0		American Psychological Association			
13	Journals Of Gerontology Series B-Psychological Sciences And Social Sciences	0	0		The Gerontological Society of America			
14	Psychophysiology	0	0		Wiley			
15	Psychology And Psychotherapy-Theory Research And Practice	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
16	Psycho-Oncology	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
17	International Psychogeriatrics	0	0		Cambridge University Press			
18	Journal Of Applied Sport Psychology	1	1	Broad audience	Taylor & Francis	Plain language summary	Author	O
19	Clinical Neuropsychologist	0	0		Taylor & Francis			
20	Stress And Health	0	0		Wiley			
21	Cognitive Psychology	1	0	Not specified	Elsevier	Highlights		
22	Social Cognitive And Affective Neuroscience	0	0		Oxford University Press			
23	Journal Of Experimental Psychology-Human Perception And Performance	0	0		American Psychological Association			
24	Neuropsychology	0	0		American Psychological Association			
25	Biological Psychology	1	0	Not specified	Elsevier	Highlights		

26	Eating Disorders	0	0		Taylor & Francis			
27	Frontiers In Human Neuroscience	0	0		Frontiers Media			
28	Journal Of Memory And Language	0	0		Elsevier			
29	Journal Of Experimental Psychology-Learning Memory And Cognition	0	0		American Psychological Association			
30	Developmental Psychobiology	0	0		American Psychological Association			
31	Journal Of Sport & Exercise Psychology	0	0		Human Kinetics			
32	International Journal Of Psychophysiology	1	0	Not specified	Elsevier	Highlights		
33	Journal Of The International Neuropsychological Society	0	0		Cambridge University Press			
34	Human Factors	0	0		SAGE			
35	Neurobiology Of Learning And Memory	0	0		Elsevier			
36	Neuropsychological Rehabilitation	0	0		Taylor & Francis			
37	Journal Of Neuropsychology	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
38	Archives Of Clinical Neuropsychology	0	0		Elsevier			
39	Ergonomics	0	0		Bentham Open			

40	Journal Of Studies On Alcohol And Drugs	0	0		Rutgers			
41	Clinical Child Psychology And Psychiatry	0	0		SAGE			
42	Research Quarterly For Exercise And Sport	0	0		Taylor & Francis			
43	Journal Of Experimental Psychology-Animal Learning And Cognition	0	0		American Psychological Association			
44	Journal Of Clinical And Experimental Neuropsychology	0	0		Taylor & Francis			
45	Cognitive Neuropsychology	0	0		Taylor & Francis			
46	Psychosomatics	0	0		Elsevier			
47	Neuropsychobiology	0	0		American Psychological Association			
48	Multisensory Research	0	0		BRILL			
49	Developmental Neuropsychology	0	0		Taylor & Francis			
50	Applied Neuropsychology-Adult	0	0		Taylor & Francis			
	Urology & Nephrology N=50							
1	Nature Reviews Nephrology	0	0		Springer Nature			
2	European Urology	1	1	Non-medical	Elsevier	Patient Summary	Author	M
3	Nature Reviews Urology	0	0		Springer Nature			
4	Kidney International	0	0		Elsevier			

5	Kidney International Supplements	0	0		Elsevier			
6	Journal Of The American Society Of Nephrology	1	0	General reader of JASN	American Society of Nephrology	Significance Statement		
7	American Journal Of Kidney Diseases	1	0	Readers of the journal	Elsevier	Plain language summaries		
8	Clinical Journal Of The American Society Of Nephrology	0			American Society of Nephrology			
9	European Urology Oncology	1	0	Non-medical	Elsevier	Patient Summary	Author	M
10	Journal Of Urology	0	0		American Urological Association Education and Research			
11	European Urology Open Science (formerly) European Urology Supplements	1	1	Non-medical	Elsevier	Patient Summary	Author	M
12	European Urology Focus	1	1	Non-medical	Elsevier	Patient Summary	Author	M
13	Nephrology Dialysis Transplantation	0	0		Oxford University Press			
14	Aging Male	0	0		Taylor & Francis			
15	BJU International	0	0		BJU International			
16	Prostate Cancer And Prostatic Diseases	0	0		Digital Science Press			
17	World Journal Of Mens Health	0	0		Korean Society for Sexual Medicine and Andrology			
18	Seminars In Nephrology	0	0		Elsevier			

19	Sexual Medicine Reviews	0	0		Elsevier			
20	Clinical Kidney Journal	0	0		Oxford University Press			
21	World Journal Of Urology	0	0		Springer Nature			
22	Kidney International Reports	0	0		Elsevier			
23	Prostate	0	0		Wiley			
24	Journal Of Nephrology	0	0		Springer Nature			
25	Journal Of Sexual Medicine	0	0		Elsevier			
26	American Journal Of Nephrology	0	0		Karger			
27	Minerva Urologica E Nefrologica	0	0		Edizioni Minerva Medica			
28	Pediatric Nephrology	0	0		Springer Nature			
29	Kidney Research And Clinical Practice	0	0		The Korean Society of Nephrology			
30	Journal Of Renal Nutrition	0	0		Elsevier			
31	Advances In Chronic Kidney Disease	1	0	Not specified	Elsevier	Clinical summary		
32	Urologic Oncology-Seminars And Original Investigations	1	0	Not specified	Elsevier	Highlights		
33	Seminars In Dialysis	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
34	Urolithiasis	0	0		Springer Nature			
35	American Journal Of Physiology-Renal Physiology	0	0		American Physiological Society			
36	International Journal Of Urology	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O

37	Asian Journal Of Andrology	0	0		Wolters Kluwer Health			
38	Bladder Cancer	0	0		IOS Press			
39	Kidney Diseases	0	0		Karger			
40	Translational Andrology And Urology	0	0		AME			
41	Current Urology Reports	0	0		Springer Nature			
42	Journal Of Endourology	0	0		Mary Ann Liebert			
43	International Journal Of Impotence Research	0	0		Springer Nature			
44	Current Opinion In Nephrology And Hypertension	1	0	Not specified	Wolters Kluwer Health	Key Points		
45	International Urogynecology Journal	0	0		Springer Nature			
46	Clinical Genitourinary Cancer	1	0	Not specified	Elsevier	Highlights		
47	Nephron	0	0		Karger			
48	International Neurourology Journal	0	0		Korean Continence Society			
49	Clinical And Experimental Nephrology	0	0		Springer Nature			
50	Neurourology And Urodynamics	0	0		Wiley			
	Respiratory system N=50							
1	Lancet Respiratory Medicine	0	0		Elsevier			
2	American Journal Of Respiratory And Critical Care Medicine	0	0		American Thoracic Society			

3	European Respiratory Journal	0	0		European Respiratory Society			
4	Journal Of Thoracic Oncology	0	0		Elsevier			
5	Journal Of Heart And Lung Transplantation	0	0		Elsevier			
6	Chest	0	0		American College of Chest Physicians			
7	Thorax	1	0	Not specified	BMJ Publishing Group & British Thoracic Society	Key Messages		
8	European Respiratory Review	0	0		European Respiratory Society			
9	American Journal Of Respiratory Cell And Molecular Biology	0	0		American Thoracic Society			
10	Annals Of The American Thoracic Society	0	0		American Thoracic Society			
11	Translational Lung Cancer Research	0	0		AME Publishing Company			
12	Respirology	1	0	Not specified	Wiley	Summary at a Glance		
13	Lung Cancer	1	0	Not specified	Elsevier	Highlights		
14	Respiratory Research	0	0		Springer Nature			
15	Journal Of Cystic Fibrosis	1	0	Not specified	Elsevier	Highlights		
16	American Journal Of Physiology-Lung Cellular And Molecular Physiology	0	0		American Physiological Society			

17	Journal Of Thoracic And Cardiovascular Surgery	1	0	Not specified	Elsevier	Central Message & Perspective Statement		
18	Archivos De Bronconeumologia	0	0		Elsevier			
19	Annals Of Thoracic Surgery	0	0		Elsevier			
20	Journal Of Asthma And Allergy	1	1	Public	Dove Medical Press	Plain language summary	Author	O
21	European Journal Of Cardio-Thoracic Surgery	0	0		Oxford University Press			
22	Therapeutic Advances In Respiratory Disease	0	0		SAGE			
23	Expert Review Of Respiratory Medicine	1	1	Patients	Taylor & Francis	Plain language summary	Author	O
24	Respiration	0	0		Karger			
25	Pulmonology	0	0		Elsevier			
26	Thoracic Cancer	1	0	Not specified	Wiley	Key Points		
27	Respiratory Medicine	1	0	Not specified	Elsevier	Highlights		
28	Pulmonary Pharmacology & Therapeutics	1	0	Not specified	Elsevier	Highlights		
29	Chronic Obstructive Pulmonary Diseases-Journal Of The COPD Foundation	0	0		COPD Foundation			
30	International Journal Of Chronic Obstructive Pulmonary Disease	0	0		Dove Medical Press			

31	BMC Pulmonary Medicine	0	0		Springer Nature			
32	Journal Of Breath Research	0	0		IOP Publishing			
33	Current Opinion In Pulmonary Medicine	1	0	Not specified	Wolters Kluwer	Key Points		
34	Tuberculosis	1	0	Not specified	Elsevier	Highlights		
35	Seminars In Respiratory And Critical Care Medicine	0	0		Thieme			
36	Pediatric Pulmonology	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
37	Pulmonary Circulation	0	0		SAGE			
38	Journal Of Thoracic Disease	0	0		AME Publishing Company			
39	Clinics In Chest Medicine	0	0		Elsevier			
40	Npj Primary Care Respiratory Medicine	0	0		Springer Nature			
41	Journal Of Aerosol Medicine And Pulmonary Drug Delivery	0	0		Mary Ann Liebert			
42	Sleep And Breathing	0	0		Springer Nature			
43	Paediatric Respiratory Reviews	1	0	Not specified	Elsevier	Highlights		
44	Journal Of Cardiothoracic And Vascular Anesthesia	1	0	Not specified	Elsevier	Highlights		
45	Jornal Brasileiro De Pneumologia	NA	NA					
46	Lung	0	0		Springer Nature			

47	Clinical Respiratory Journal	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
48	Journal Of Asthma	0	0		Taylor & Francis			
49	Experimental Lung Research	0	0		Taylor & Francis			
50	Chronic Respiratory Disease	0	0		SAGE			
	Clinical Neurology N=50							
1	Lancet Neurology	0	0		Elsevier			
2	Nature Reviews Neurology	0	0		Springer Nature			
3	Alzheimers & Dementia	0	0		Wiley			
4	JAMA Neurology	1	0	Not specified	JAMA Network	Key Points		
5	Acta Neuropathologica	0	0		Springer Nature			
6	Brain	0	0		Oxford University Press			
7	Neuro-Oncology	1	0	Not specified	Oxford University Press	Key Points		
8	Sleep Medicine Reviews	0	0		Elsevier			
9	Annals Of Neurology	0	0		Wiley			
10	Movement Disorders	0	0		Wiley			
11	Journal Of Neurology Neurosurgery And Psychiatry	0	0		BMJ Publishing Group			
12	Neurology	0	0		Wolters Kluwer Health			
13	Brain Stimulation	0	0		Elsevier			

14	Neurology-Neuroimmunology & Neuroinflammation	0	0		Wolters Kluwer Health			
15	Neuropathology And Applied Neurobiology	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
16	Stroke	0	0		American Heart Foundation			
17	Neurotherapeutics	0	0		Elsevier			
18	Neuroscientist	0	0		SAGE			
19	Epilepsy Currents	0	0		SAGE			
20	Journal Of Headache And Pain	0	0		Springer Nature			
21	Alzheimers Research & Therapy	0	0		Springer Nature			
22	Journal Of Stroke	0	0		Korean Stroke Society			
23	Pain	1	0	Wider community	International Association for the Study of Pain	Plain language summary	Outsourced	O
24	Translational Stroke Research	0	0		Springer Nature			
25	Bipolar Disorders	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
26	Therapeutic Advances In Neurological Disorders	0	0		SAGE			
27	Brain Pathology	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
28	Multiple Sclerosis Journal	0	0		SAGE			
29	Cephalalgia	0	0		SAGE			
30	European Journal Of Neurology	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O

31	Headache	0	0		Wiley			
32	Epilepsia	0	0		Wiley			
33	Sleep	1	0	Not specified	Oxford University Press	Statement of Significance		
34	Journal Of Pain	1	0	Not specified	Elsevier	Highlights		
35	Neurology And Therapy	1	1	Non-specialists, public, non-academics	Springer Nature	Plain language summary	Author	O
36	CNS Drugs	1	1	Non-specialists, public, non-academics	Springer Nature	Plain language summary	Author	O
37	Pain And Therapy	1	1	Non-specialists, public, non-academics	Springer Nature	Plain language summary	Author	O
38	Current Opinion In Neurology	1	0	Not specified	Wolters Kluwer Health	Key Points		
39	Developmental Medicine And Child Neurology	0	0		Wiley			
40	Nature And Science Of Sleep	0	0		Dove Medical Press			
41	European Archives Of Psychiatry And Clinical Neuroscience	0	0		Springer Nature			
42	Journal Of Neurotrauma	0	0		Mary Ann Liebert			

43	International Journal Of Stroke	0	0		Wiley			
44	Psychiatry And Clinical Neurosciences	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
45	International Journal Of Neuropsychopharmacology	0	0		Oxford University Press			
46	Journal Of Neurosurgery	0	0		American Association of Neurological Surgeons			
47	Current Neurology And Neuroscience Reports	0	0		Springer Nature			
48	Progress In Neuro-Psychopharmacology & Biological Psychiatry	1	0	Not specified	Elsevier	Highlights		
49	Pain Physician	0	0		American Society of Interventional Pain Physicians			
50	Journal Of Neurogastroenterology And Motility	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
	Gastroenterology & Hepatology N=50							
1	Nature Reviews Gastroenterology & Hepatology	0	0		Springer Nature			
2	Journal Of Hepatology	1	1	Non-medical	Elsevier	Lay Summary	Author	M
3	Gut	1	0	Not specified	BMJ Publishing Group	Summary box		
4	Gastroenterology	1	1	Lay	Elsevier	Lay Summary	Author	M

5	Lancet Gastroenterology & Hepatology	0	0		Elsevier			
6	Hepatology	0	0		Wiley			
7	Liver Cancer	0	0		Karger			
8	Clinical Gastroenterology And Hepatology	1	0	Wider community	Wolters Kluwer Health	Plain language summary	Outsourced	O
9	American Journal Of Gastroenterology	0	0		Wolters Kluwer Health			
10	Gut Microbes	0	0		Taylor & Francis			
11	Endoscopy	0	0		Thieme			
12	Gastrointestinal Endoscopy	0	0		Elsevier			
13	Cellular And Molecular Gastroenterology And Hepatology	0	0		Elsevier			
14	Journal Of Crohns & Colitis	0	0		Oxford University Press			
15	Alimentary Pharmacology & Therapeutics	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
16	Digestive Endoscopy	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
17	Journal Of Gastroenterology	0	0		Springer Nature			
18	Gastric Cancer	0	0		Springer Nature			
19	Hepatobiliary Surgery And Nutrition	0	0		AME Publishing Group			
20	Journal Of Hepato-Biliary-Pancreatic Sciences	0	0		Wiley			

21	Clinics In Liver Disease	0	0		Elsevier			
22	Seminars In Liver Disease	0	0		Thieme			
23	Clinical And Molecular Hepatology	1	0	Not specified	The Korean Association for the Study of the Liver	Highlight		
24	Hepatology International	0	0		Springer Nature			
25	Liver International	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
26	Liver Transplantation	0	0		Wiley			
27	Helicobacter	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
28	World Journal Of Gastroenterology	0	0		Baishideng Publishing Group			
29	Endoscopic Ultrasound	0	0		Spring Media Publishing			
30	Inflammatory Bowel Diseases	0	0		Oxford University Press			
31	Annals Of Gastroenterological Surgery	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
32	Hepatology Communications	0	0		Wiley			
33	Journal Of Neurogastroenterology And Motility	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
34	United European Gastroenterology Journal	0	0		SAGE			
35	Diseases Of The Colon & Rectum	0	0		American Society of Colon and Rectal Surgeons			
36	Gut And Liver	0	0		Gut and Liver			

37	Clinical And Translational Gastroenterology	0	0		Wolters Kluwer Health			
38	Therapeutic Advances In Gastroenterology	1	1	General public	SAGE	Plain language summary	Author	O
39	Hepatology Research	0	0		Wiley			
40	Esophagus	0	0		Springer Nature			
41	Gut Pathogens	0	0		Springer Nature			
42	Journal Of Clinical And Translational Hepatology	0	0		Xia & He Publishing			
43	Digestive And Liver Disease	0	0		Elsevier			
44	American Journal Of Physiology-Gastrointestinal And Liver Physiology	0	0		American Physiological Society			
45	Journal Of Gastroenterology And Hepatology	0	0		Wiley			
46	Pancreatology	0	0		Elsevier			
47	Expert Review Of Gastroenterology & Hepatology	1	1	Patients, caregivers	Taylor & Francis	Plain language summary	Author	O
48	Gastroenterology Clinics Of North America	0	0		Elsevier			
49	Colorectal Disease	0	0		Wiley			
50	Techniques In Coloproctology	0	0		Springer Nature			

	Ophthalmology N=50							
1	Progress In Retinal And Eye Research	1	0	Not specified	Elsevier	Highlights		
2	Ophthalmology	0	0		Elsevier			
3	Jama Ophthalmology	0	0		JAMA Network			
4	Annual Review Of Vision Science	1	0	Not specified	Annual Reviews	Summary Points		
5	Survey Of Ophthalmology	0	0		Elsevier			
6	American Journal Of Ophthalmology	0	0		Elsevier			
7	Ocular Surface	1	0	Not specified	Elsevier	Highlights		
8	Investigative Ophthalmology & Visual Science	0	0		Association for Research in Vision & Ophthalmology			
9	British Journal Of Ophthalmology	0	0		BMJ Publishing Group			
10	Retina-The Journal Of Retinal And Vitreous Diseases	1	0	Wider community	Wolters Kluwer Health	Plain language summary	Outsourced	O
11	Clinical And Experimental Ophthalmology	0	0		Wiley			
12	Eye	0	0		Springer Nature			
13	Acta Ophthalmologica	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
14	Current Opinion In Ophthalmology	1	0	Not specified	Wolters Kluwer Health	Key Points		
15	Journal Of Refractive Surgery	0	0		Helio			
16	Ophthalmology And Therapy	1	1	Non-specialists,	Springer Nature	Plain language summary	Author	O

				public, non-academics				
17	Experimental Eye Research	1	0	Not specified	Elsevier	Highlights		
18	Journal Of Cataract And Refractive Surgery	1	0	Wider community	Wolters Kluwer Health	Plain language summary	Outsourced	O
19	Translational Vision Science & Technology	0	0		Association for Research in Vision & Opthamology			
20	Eye And Vision	0	0		Springer Nature			
21	Ophthalmologica	0	0		Karger			
22	Visual Neuroscience	0	0		Oxford University Press			
23	Graefes Archive For Clinical And Experimental Ophthalmology	0	0		Springer Nature			
24	Ophthalmic And Physiological Optics	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
25	Contact Lens & Anterior Eye	0	0		Elsevier			
26	Ocular Immunology And Inflammation	0	0		Taylor & Francis			
27	Journal Of Neuro-Ophthalmology	0	0		Wolters Kluwer Health			
28	Ophthalmic Research	0	0		Karger			
29	Asia-Pacific Journal Of Ophthalmology	0	0		Asia-Pacific Academy of Ophthalmology			
30	Clinical And Experimental Optometry	0	0		Taylor & Francis			

31	Journal Of Ocular Pharmacology And Therapeutics	0	0		Mary Ann Liebert			
32	Cornea	1	0	Wider community	Wolters Kluwer Health	Plain language summary	Outsourced	O
33	European Journal Of Ophthalmology	0	0		SAGE			
34	Journal Of Glaucoma	1	0	Wider community	Wolters Kluwer Health	Plain language summary	Outsourced	O
35	Japanese Journal Of Ophthalmology	0	0		Springer Nature			
36	Current Eye Research	0	0		Taylor & Francis			
37	Documenta Ophthalmologica	0	0		Springer Nature			
38	Molecular Vision- Biology & Genetics in Vision Research	0	0		Molecular Vision			
39	Journal Of Vision	0	0		Association for Research in Vision & Ophthalmology			
40	BMC Ophthalmology	0	0		Springer Nature			
41	International Ophthalmology	0	0		Springer Nature			
42	Eye & Contact Lens-Science And Clinical Practice	1	0	Wider community	Wolters Kluwer Health	Plain language summary	Outsourced	O
43	Seminars In Ophthalmology	0	0		Taylor & Francis			
44	Optometry And Vision Science	1	0	Wider community	Wolters Kluwer Health	Plain language summary	Outsourced	O
45	Journal Of Ophthalmology	0	0		Hindawi			

46	Vision Research	1	0	Not specified	Elsevier	Highlights		
47	Canadian Journal Of Ophthalmology-Journal Canadien D Ophtalmologie	0	0		Elsevier			
48	Indian Journal Of Ophthalmology	0	0		Wolters Kluwer Health			
49	Cutaneous And Ocular Toxicology	0	0		Taylor & Francis			
50	Ophthalmic Genetics	0	0		Taylor & Francis			
	Dermatology N=50							
1	Journal Of The American Academy Of Dermatology	1	0	Not specified	Elsevier	Plain language summary	Outsourced	
2	JAMA Dermatology	1	0	Not specified	JAMA Network	Key Points		
3	British Journal Of Dermatology	1	1	Patients	Wiley	Plain language summaries	Author	O
4	Journal Of Investigative Dermatology	0	0		Elsevier			
5	American Journal Of Clinical Dermatology	1	1	Wider community	Springer Nature	Plain language summaries	Author	O
6	Contact Dermatitis	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
7	Journal Of The European Academy Of Dermatology And Venereology	0	0		Wiley			
8	Journal Der Deutschen Dermatologischen Gesellschaft	NA	NA					
9	Dermatology	0	0		Karger			
10	Burns & Trauma	0	0		Oxford University Press			

11	Dermatitis	1	0	Wider community	Wolters Kluwer Health	Plain language summary	Outsourced	O
12	Advances In Wound Care	1	0	Wider community	Mary Ann Liebert	Plain language summary	Outsourced	O
13	Pigment Cell & Melanoma Research	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
14	Journal Of Dermatological Science	0	0		Elsevier			
15	Advances in Dermatology & Venereology	0	0		Acta Dermato-Venereologica			
16	Mycoses	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
17	Lasers In Surgery And Medicine	0	0		Wiley			
18	Journal Of Dermatology	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
19	Experimental Dermatology	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
20	Wound Repair And Regeneration	0	0		Wiley			
21	Melanoma Research	1	0	Wider community	Wolters Kluwer Health	Plain language summary	Outsourced	O
22	Clinics In Dermatology	0	0		Elsevier			
23	Skin Pharmacology And Physiology	0	0		Karger			
24	Dermatologic Clinics	0	0		Elsevier			
25	Clinical And Experimental Dermatology	0	0		Wiley			
26	Dermatologic Surgery	0	0		American Society for Dematological Surgery			

27	Journal Of Dermatological Treatment	0	0		Taylor & Francis			
28	European Journal Of Dermatology	0	0		John Libbey Eurotext			
29	International Wound Journal	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
30	Dermatology And Therapy	1	1	Non-specialists, public, non-academics	Springer Nature	Plain language summary	Author	O
31	Photodermatology Photoimmunology & Photomedicine	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
32	Archives Of Dermatological Research	0	0		Springer Nature			
33	International Journal Of Cosmetic Science	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
34	Journal Of Tissue Viability	1	0	Not specified	Elsevier	Highlights		
35	Australasian Journal Of Dermatology	0	0		Wiley			
36	Dermatologic Therapy	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
37	Burns	1	0	Not specified	Elsevier	Highlights		
38	International Journal Of Dermatology	0	0		Wiley			
39	Journal Of Cosmetic Dermatology	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
40	Indian Journal Of Dermatology Venereology & Leprology	0	0		Scientific Scholar on behalf of Indian Association of Dermatologists			

41	Clinical Cosmetic And Investigational Dermatology	1	1	Wider community	Dove Medical Press	Plain language summary	Author	O
42	Skin Research And Technology	1	0	Lay audience	Wiley	Lay summaries	Outsourced	O
43	Advances In Skin & Wound Care	0	0		European Wound Management Association			
44	Journal Of Cosmetic And Laser Therapy	0	0		Taylor & Francis			
45	Journal Of Drugs In Dermatology	0	0		SanovaWorks			
46	Journal Of Cutaneous Medicine And Surgery	0	0		SAGE			
47	Journal Of Wound Care	0	0		MA Healthcare			
48	International Journal Of Lower Extremity Wounds	0	0		SAGE			
49	Giornale Italiano Di Dermatologia E Venereologia	NA	NA					
50	Dermatology Practical & Conceptual	0	0		Mattioli Health			

[1] summary that is not the scientific abstract

* No

** Yes

Appendix A (ii)

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	22
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	23
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	25
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	25
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	26
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	27
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	27
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	NA
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	27-28
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	28
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	28-29

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	NA
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	29
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	30-31
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	32
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	NA
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	32-37
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	30
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	38
Limitations	20	Discuss the limitations of the scoping review process.	40-41
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	42
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	46

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. Ann Intern Med. 2018;169:467–473. doi: 10.7326/M18-0850.

Appendix B (i)

Assessing compliance for all elements and sub-elements (part two)

Element	Sub-element	Example from PLS author instructions	Method/criteria for assessing compliance	Compliance scoring Full = 2, Partial = 1, Non = 0
Word count/PLS length	Maximum number of words	No more than 250 words.	Copied the PLS text into a document in MS Word. Recorded the number of words and compared with PLS author instructions.	Full - within 5% +/- maximum word limit. Partial - 5-10% +/- maximum word limit. Non - > 10% +/- maximum word limit.
	PLS length	Two or three short sentences.	Viewed the PLS and noted whether it was written in paragraph style or similar.	Full - 100% correct number of sentences of stated length. Partial - ≥ 75% correct number of sentences of stated length. Non - < 75% number of sentences of stated length.
Content	Based on manuscript/reflects manuscript	They must reflect the actual information reported in the published study.	Read the PLS and entire journal article then compared both texts.	Full - PLS was clearly based on the manuscript. Partial - Unclear if PLS was based on the manuscript. Non - PLS was not based on the manuscript.
	Background	Why was the study done?	Read the PLS and entire journal article then compared both texts.	Full - Background included in the PLS. Partial - Unclear if background included in the PLS. Non - Background not included in the PLS.

	Methods	What did the researchers do and find?	Read the PLS and entire journal article then compared both texts.	Full - Methods included in the PLS. Partial - Unclear if methods included in the PLS. Non - Methods not included in the PLS.
	Main findings/take-home message	What do the results mean?	Read the PLS and entire journal article then compared both texts.	Full - Main findings/take-home message included in the PLS Partial - Unclear if main findings/take-home message included in the PLS. Non - Main findings/take-home message not included in the PLS.
	Impact/"so what" of research	What is the objective influence on the wider field?	Read the PLS and article Discussion then compared both texts.	Full - Impact/"so what" of research included in the PLS. Partial - Unclear if impact/"so what" of research included in the PLS. Non - Impact/"so what" of research not included in the PLS.
	Other	Both merits and limitations should be discussed.	Read the PLS and article Discussion then compared both texts.	Full - Merits and limitations (or relevant text) were present in PLS. Partial - Unclear if merits and limitations (or relevant text) were present in PLS. Non - Merits and limitations (or relevant text) were not present in PLS.
Structure	Bullet points	Use bullet points.	Viewed the PLS and noted whether it contained bullet points.	Full - used bullet points. Partial - used some bullet points. Non - used no bullet points.

	Paragraph style or similar	Use short, clear sentences, short paragraphs.	Viewed the PLS and noted whether it was written in paragraph style or similar.	Full - 100% correct number of sentences of stated length. Partial - ≥ 75% correct number of sentences of stated length. Non - < 75% number of sentences of stated length.
Wording/language	Plain English/easy to understand	Should be written in an easy-to-understand manner.	Based on score for the use of jargon	Full - maximum of 2% rare words. Partial - 3-5% rare words. Non - >5 % rare words.
	Active voice	Sentences should be written in the active voice, rather than the passive voice.	Analysed the PLS using an online real-time editor [6] and noted the number of times passive voice was used.	Full - No sentences in passive voice. Partial - 1-3 sentences in passive voice. Non - > 3 sentences in passive voice.
	Person-centred language	Use person-centred language rather than focussing on the condition/illness or disability.	We established a priori criteria using principles of person-centred language that is based on guidance from resources produced by several peak bodies [13]. - Using “person with X” or “person being treated for X” rather than “X disease” i.e., describing the condition(s) that a person has, not what a person is - Avoiding words such as “sufferer”, “victim” or “afflicted” - When referring to caregivers, using terms such as “caring for/supporting a person with X” or “living with the impact of X” rather than “burden of caring” or “carer burden”	Full - All wording person-centred. Partial - 1 instance of non-person-centred language. Non - >1 instance of non-person-centred language.
	Use first person	Write in the first person.	Read the PLS and noted whether it was written in the first person.	Full - All sentences in the first person Partial - 1-2 sentences in the first person. Non - >2 sentences in the first person.

	Reading level/readability	Suitable for someone in high school.	Analysed the PLS using an online real-time editor* [6] and noted the reading level.	Full - Grade 8 reading level. Partial - Grade 9 or 10 reading level. Non - over grade 10 reading level.
	Other	Use absolute numbers instead of statistics and percentages.	Read the PLS and noted whether it conformed to the PLS author instructions.	Full - Entire PLS conformed to the instruction. Partial - if instruction states to avoid X e.g., statistics, 1 use of statistics. Non - > 1 use of statistics.
Jargon, Acronyms & Abbreviations	Jargon - explain or avoid	Avoid jargon. If you need to use a technical term, please explain it the first time you use it.	Analysed the PLS using the De-Jargoniser ** tool. Noted the percentage of rare words.	Full - maximum of 2% rare words. Partial - 3-5% rare words. Non - >5 % rare words.
	Abbreviations - explain or avoid	Avoid abbreviations. If you need to use an abbreviation, please explain it the first time you use it.	Read the PLS and noted whether it contained any abbreviation.	Full - no abbreviations. Partial - maximum of 2 unique abbreviations not explained before first time used. Non - >2 unique abbreviations not explained before first time used.

* https://shell.techlab.works/ (Ayre et al., 2023)

** https://scienceandpublic.com/ (Rakedzon et al., 2017)

Appendix B (ii)

Readability and complex language scores and ratings for all journals

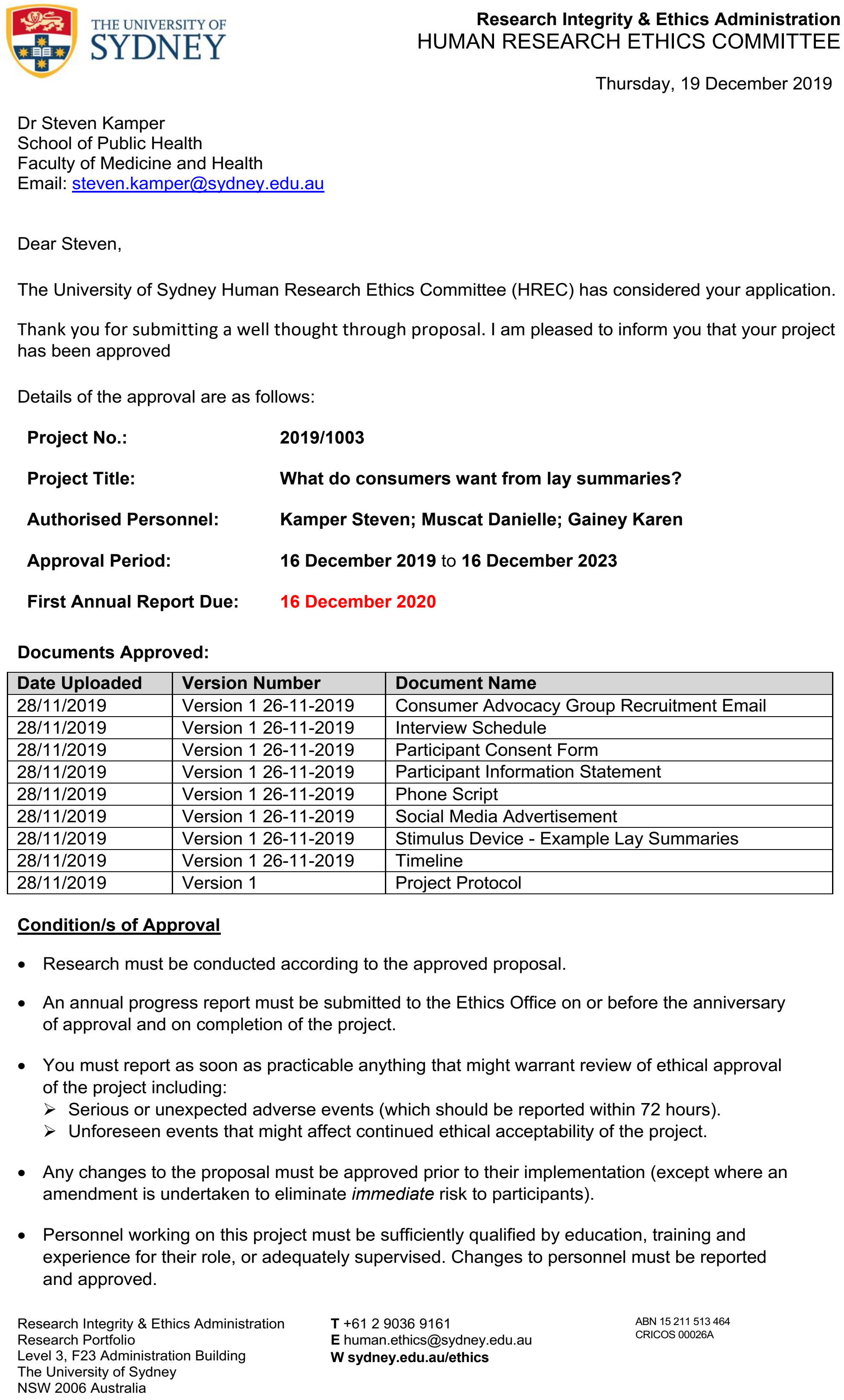
	Readability (Reading grade level)									Complex Words (%)								
	PLS 1			PLS 2			PLS 3			PLS 1			PLS 2			PLS 3		
Journal name	**Raw**	**Edited[1]**	**Rating[2]**	**Raw**	**Edited**	**Rating**	**Raw**	**Edited**	**Rating**	**Raw**	**Edited**	**Rating[3]**	**Raw**	**Edited**	**Rating**	**Raw**	**Edited**	**Rating**
American Journal of Clinical Dermatology	15.9	14.6	Poor	18.4	17.0	Poor	13.1	10.2	Poor	26.3	25.8	Poor	36.2	31.7	Poor	33.8	26.0	Poor
British Journal Of Dermatology	15.3	15.0	Poor	14.4	14.4	Poor	17.8	16.2	Poor	38.8	37.2	Poor	26.9	27.0	Poor	35.8	34.7	Poor
Cancer	17.9	17.5	Poor	17.1	15.1	Poor	16.2	15.6	Poor	36.4	36.4	Poor	42.2	35.5	Poor	30.3	26.3	Poor
Clinical Cosmetic and Investigational Dermatology	13.8	13.2	Poor	NA[4]	NA	NA	NA	NA	NA	28.2	26.2	Poor	NA	NA	NA	NA	NA	NA
CNS Drugs	15.4	13.1	Poor	13.8	12.0	Poor	16.2	15.4	Poor	33.0	26.7	Poor	23.0	16.8	Poor	35.1	33.0	Poor
Dermatology and Therapy	16.0	15.0	Poor	19.8	18.2	Poor	13.2	12.2	Poor	30.5	27.5	Poor	27.3	27.7	Poor	28.0	25.7	Poor
European Urology	17.7	17.7	Poor	17.1	15.9	Poor	19.8	19.8	Poor	49.8	49.8	Poor	44.9	39.8	Poor	47.2	47.2	Poor
European Urology Focus	19.8	18.8	Poor	16.5	16.5	Poor	21.2	21.2	Poor	36.9	33.1	Poor	34.4	34.4	Poor	39.5	39.5	Poor
European Urology Oncology	14.6	14.6	Poor	16.5	16.5	Poor	18.2	18.2	Poor	34.4	34.4	Poor	31.6	31.6	Poor	32.3	32.3	Poor
European Urology Open Science	15.0	12.5	Poor	18.2	18.2	Poor	20.3	19.3	Poor	28.9	28.9	Poor	27.9	27.9	Poor	43.1	41.0	Poor

Expert Review of Respiratory Medicine	16.5	16.1	Poor	18.2	17.1	Poor	NA	NA	NA	37.5	36.9	Poor	21.3	19.2	Poor	NA	NA	NA
Journal of Applied Sport Psychology	20.3	19.3	Poor	17.7	17.7	Poor	21.2	20.3	Poor	28.9	28.9	Poor	8.5	8.5	Good	32.0	32.0	Poor
Journal of Asthma and Allergy	16.9	16.3	Poor	18.4	16.8	Poor	18.2	17.3	Poor	33.2	32.1	Poor	37.4	32.6	Poor	32.5	29.6	Poor
Journal Of Cardiac Failure	14.8	13.3	Poor	15.9	15.9	Poor	15.9	15.9	Poor	36.2	36.2	Poor	29.8	29.8%	Poor	36.0	36.0	Poor
Journal Of Hepatology	19.0	19.0	Poor	15.0	11.9	Poor	17.7	16.5	Poor	41.9	37.0	Poor	47.3	37.0	Poor	48.7	43.8	Poor
Neurology and Therapy	17.2	17.0	Poor	14.6	14.2	Poor	NA	NA	NA	32.5	31.7	Poor	21.9	16.5	Poor	NA	NA	NA
Ophthalmology and Therapy	17.2	16.0	Poor	NA	NA	NA	NA	NA	NA	34.4	28.3	Poor	NA	NA	NA	NA	NA	NA
Pain And Therapy	13.3	12.6	Poor	14.6	14.6	Poor	NA	NA	NA	36.8	36.5	Poor	25.8	25.8	Poor	NA	NA	NA
Rheumatology And Therapy	14.8	14.4	Poor	12.0	10.3	Poor	14.6	13.0	Poor	41.9	40.9	Poor	11.9	11.9	Poor	22.6	22.6	Poor
Therapeutic Advances in Gastroenterology	16.9	16.7	Poor	15.9	15.8	Poor	16.8	15.8	Poor	31.6	30.1	Poor	25.8	24.8	Poor	37.5	32.1	Poor

1. Edited score is the score after excluding words.
2. A “good” rating was given if the reading level was > 8, 9 or 10, and a “poor” rating was given if the reading level was >10.
3. An “excellent” rating was given if the complex language score was ≤5%, “good” if it was 5-10% and “poor” if it was > 10%.
4. No plain language summary available for analysis.

Appendix C (i)

Ethics approval letter



THE UNIVERSITY OF
SYDNEY

Research Integrity & Ethics Administration
HUMAN RESEARCH ETHICS COMMITTEE

Thursday, 19 December 2019

Dr Steven Kamper
School of Public Health
Faculty of Medicine and Health
Email: steven.kamper@sydney.edu.au

Dear Steven,

The University of Sydney Human Research Ethics Committee (HREC) has considered your application.

Thank you for submitting a well thought through proposal. I am pleased to inform you that your project has been approved

Details of the approval are as follows:

Project No.:	**2019/1003**
Project Title:	**What do consumers want from lay summaries?**
Authorised Personnel:	**Kamper Steven; Muscat Danielle; Gainey Karen**
Approval Period:	**16 December 2019** to **16 December 2023**
First Annual Report Due:	**16 December 2020**

Documents Approved:

Date Uploaded	Version Number	Document Name
28/11/2019	Version 1 26-11-2019	Consumer Advocacy Group Recruitment Email
28/11/2019	Version 1 26-11-2019	Interview Schedule
28/11/2019	Version 1 26-11-2019	Participant Consent Form
28/11/2019	Version 1 26-11-2019	Participant Information Statement
28/11/2019	Version 1 26-11-2019	Phone Script
28/11/2019	Version 1 26-11-2019	Social Media Advertisement
28/11/2019	Version 1 26-11-2019	Stimulus Device - Example Lay Summaries
28/11/2019	Version 1 26-11-2019	Timeline
28/11/2019	Version 1	Project Protocol

Condition/s of Approval

- Research must be conducted according to the approved proposal.
- An annual progress report must be submitted to the Ethics Office on or before the anniversary of approval and on completion of the project.
- You must report as soon as practicable anything that might warrant review of ethical approval of the project including:
  - ➢ Serious or unexpected adverse events (which should be reported within 72 hours).
  - ➢ Unforeseen events that might affect continued ethical acceptability of the project.
- Any changes to the proposal must be approved prior to their implementation (except where an amendment is undertaken to eliminate *immediate* risk to participants).
- Personnel working on this project must be sufficiently qualified by education, training and experience for their role, or adequately supervised. Changes to personnel must be reported and approved.

Appendix C (ii)

Interview Guide

There are no wrong answers but rather differing points of view. Please feel free to share your point of view even if it differs from what others have said. Keep in mind that we're just as interested in negative comments about plain language summaries and health information as positive comments, and at times the negative comments are the most helpful.

You've probably noticed the ‘recording’ icon on your screen. We're recording the audio from the session via ZOOM because we don't want to miss any of your comments. We won’t be recording any video, nor will we be saving the chat transcript.

Focus Group Specific
People often say very helpful things in these discussions, and we can't write fast enough to get them all down. I might interrupt you during the session to keep things on track and to time. We can always continue a discussion later via email.

We will be on a first name basis today; however, we won't use any names in our reports. You may be assured of complete confidentiality. Well, let's begin. Let's find out some more about each other by going around the group. Please tell us your name and where you live.

The first part of the session will be about how you search for health information.

The second part of the session will be about understanding your views about plain language summaries.

Introduce self and where this study fits into my PhD.

Question 1. Where do you search for health information?

- Internet Searches
- Scientific Journals
- Blogs
- Medical Practitioners
- Forums / Online support groups e.g., Facebook

Question 2. What draws you to those sources?

Question 3. What health information topics or conditions do you most look for offline and online?

Question 4. What motivates you to search for health information? Has it varied through different stages of your illness?

To make sure we're on the same page, what is your understanding on a plain language summary?

Question 5. How many plain language summaries have you read in the past 2 years?

Question 6. How did you find/locate the plain language summary?

Introduce document – Example Plain language summaries

Question 7. What did you like about the plain language summary?

Question 8. What did you dislike about the plain language summary?

Question 9. If you could develop the ideal plain language summary i.e., make them more useful, what would you change about them or what do you think is important about them in terms of the following:

- Content
  - Key information
  - Take home message
  - Easy of reading
  - What use of jargon, acronyms and abbreviations would be appropriate?
- Length
  - Shorter or Longer?
  - Ideal length

- Structure
  - All text
  - Graphics
  - Videos
  - Headings
  - Sentence structure
- Consumer Involvement
  - Development
  - Distribution

Introduce document – Labels for Plain language summaries

Question 10. Label given to a plain language summary.

a. Which label(s) have you heard of before as the name for a plain language summary?
b. Which three do you prefer as the name for a plain language summary.

Question 11. Of all the things we have discussed about plain language summaries, what do you think is the most important and why?

Question 12. If you could develop the ideal LS, what would it mean for you in a practical sense? Would it impact your medical care?

Question 13. Would that then impact your medical care/treatment? If so, how?

Question 14. Have we missed anything?

Appendix C (iii)

Example plain language summaries

Example No 1 - Highlights

- Air pollution (AP) may reduce the health benefits of active travel (AT).
- We compared risk–benefit trade-off of AP and physical activity (PA) due to AT.
- In most urban environments benefits of PA outweighed risks of AP.
- If cycling replaces driving, the trade-off would be even more beneficial.

Example No 2

- **The known**: People who have experienced an acute coronary syndrome (ACS) are at high risk of further events. High blood cholesterol is an important modifiable factor that increases the risks of both initial and subsequent ACS events.
- **The new**: Only 55% of patients treated in Australia for ACS were undergoing intensive lipid-lowering therapy 6 or 12 months after their hospitalisation. The major predictor of not receiving such therapy at follow-up was its not being prescribed at hospital discharge.
- **The implications**: Improving oral lipid-lowering therapy for people who have had an ACS should prevent recurrent coronary events.

Example No 3 - Key Points

- Rheumatoid arthritis is a heterogeneous disease for which there are a variety of treatment options with biologic and nonbiologic drugs.
- Studies have demonstrated the importance of initiating treatment early in the disease course, because tight control of inflammation results in better outcomes, including less progression of structural damage.
- Accepted treatment targets include low disease activity and remission, for which several quantifiable disease activity measures are available to guide treatment.
- The role of “newer” imaging modalities, such as ultrasound and MRI, in directing the routine care of RA patients is unclear.
- Treat to target strategies remain the standard of care for RA, aiming at American College of Rheumatology/European League Against Rheumatism remission.

References

1. Tanio M, de Nazelle AJ, Gotschi T, Kahlmeier S, Rojas-Rueda D, Nieuwenhuiisen MJ, de Sa TH, Kelly P and Woodcock J. Can air pollution negate the health benefits of cycling and walking? Preventative Medicine. 2016;87, 233-236.
   DOI: 10.1016/j.ypmed.2016.02.002

2. Brieger D, D’Souza M, Hyun K, Weaver JC and Kritharides L. Intensive lipid-lowering therapy in the 12 months after an acute coronary syndrome in Australia: an observational analysis. The Medical Journal of Australia. 2019; 210(2), 80-85. DOI: https://doi.org/10.5694/mja2.12035

3. Salomon-Escoto K and Kay J. The “Treat to Target” Approach to Rheumatoid Arthritis. Rheumatic Disease Clinics of North America. 2019;45(4), 487-504. (DOI is broken) Link: https://www.sciencedirect.com/science/article/abs/pii/S0889857X19300535

Appendix C (iv)

Reporting checklist – Braun & Clarke

A tool for evaluating thematic analysis (TA) manuscripts for publication: Twenty questions to guide assessment of TA research quality.

The following list of questions appears as Table 1: A tool for evaluating thematic analysis (TA) manuscripts for publication: Twenty questions to guide assessment of TA research quality in: Braun, V. & Clarke, V. (2020) One size fits all? What counts as quality practice in (reflexive) thematic analysis?, Qualitative Research in Psychology, DOI: 10.1080/14780887.2020.1769238

Question	**Quality check Page(s)**
1. Do the authors explain why they are using thematic analysis (TA), even if only briefly?	74-75
2. Do the authors clearly specify and justify which type of TA they are using?	74-75
3. Is the use and justification of the specific type of TA consistent with the research questions or aims?	Yes
4. Is there a good 'fit' between the theoretical and conceptual underpinnings of the research and the specific type of TA (i.e. is there conceptual coherence)?	74-75
5. Is there a good 'fit' between the methods of data collection and the specific type of TA?	74-75
6. Is the specified type of TA consistently enacted throughout the paper?	Yes
7. Is there evidence of problematic assumptions about, and practices around, TA? These commonly include:	No
- Treating TA as one, homogenous, entity, with one set of – widely agreed on – procedures.	No
- Combining philosophically and procedurally incompatible approaches to TA without any acknowledgement or explanation.	No
- Confusing summaries of data topics with thematic patterns of shared meaning, underpinned by a core concept.	No
- Assuming grounded theory concepts and procedures (e.g. saturation, constant comparative analysis, line-by-line coding) apply to TA without any explanation or justification.	No
- Assuming TA is essentialist or realist, or atheoretical.	No

- Assuming TA is only a data reduction or descriptive approach and therefore must be supplemented with other methods and procedures to achieve other ends.	No
8. Are any supplementary procedures or methods justified, and necessary, or could the same results have been achieved simply by using TA more effectively?	NA
9. Are the theoretical underpinnings of the use of TA clearly specified (e.g. ontological, epistemological assumptions, guiding theoretical framework(s)), even when using TA inductively (inductive TA does not equate to analysis in a theoretical vacuum)?	74-75
10. Do the researchers strive to 'own their perspectives' (even if only very briefly), their personal and social standpoint and positioning? (This is especially important when the researchers are engaged in social justice-oriented research and when representing the 'voices' of marginal and vulnerable groups, and groups to which the researcher does not belong.)	77-78
11. Are the analytic procedures used clearly outlined, and described in terms of what the authors actually did, rather than generic procedures?	77
12. Is there evidence of conceptual and procedural confusion? For example, reflexive TA (Braun & Clarke, 2006) is the claimed approach but different procedures are outlined such as the use of a codebook or coding frame, multiple independent coders and consensus coding, inter-rater reliability measures, and/or themes are conceptualised as analytic inputs rather than outputs and therefore the analysis progresses from theme identification to coding (rather than coding to theme development).	No
13. Do the authors demonstrate full and coherent understanding of their claimed approach to TA?	77-78
14. Is it clear what and where the themes are in the report? Would the manuscript benefit from some kind of overview of the analysis: listing of themes, narrative overview, table of themes, thematic map?	80-94
15. Are reported themes topic summaries, rather than 'fully realised themes' – patterns of shared meaning underpinned by a central organising concept?	No
- If so, are topic summaries appropriate to the purpose of the research?	NA
- If the authors are using reflexive TA, is this modification in the conceptualisation of themes explained and justified?	Yes
- Have the data collection questions been used as themes?	No
- Would the manuscript benefit from further analysis being undertaken, with the reporting of fully realised themes?	No
- Or, if the authors are claiming to use reflexive TA, would the manuscript benefit from claiming to use a different type of TA (e.g. coding reliability or codebook)?	No
16. Is a non-thematic contextualising information presented as a theme? (e.g. the first theme is a topic summary providing contextualising information, but the rest of the themes reported are fully realised	No

themes). If so, would the manuscript benefit from this being presented as non-thematic contextualising information?	
17. In applied research, do the reported themes have the potential to give rise to actionable outcomes?	Yes
18. Are there conceptual clashes and confusion in the paper? (e.g. claiming a social constructionist approach while also expressing concern for positivist notions of coding reliability, or claiming a constructionist approach while treating participants' language as a transparent reflection of their experiences and behaviours)	No
19. Is there evidence of weak or unconvincing analysis such as:	
- Too many or two few themes?	No
- Too many theme levels?	No
- Confusion between codes and themes?	No
- Mismatch between data extracts and analytic claims?	No
- Too few or too many data extracts?	No
- Overlap between themes?	Some overlap
20. Do authors make problematic statements about the lack of generalisability of their results, and or implicitly conceptualise generalisability as statistical probabilistic generalisability? (see Smith, 2018)	No

Reference

Smith, B. (2018). Generalizability in qualitative research: Misunderstandings, opportunities and recommendations for the sport and exercise sciences. *Qualitative Research in Sport*, Exercise and Health, 10(1), 137-149. Available from: https://doi.org/10.1080/2159676X.2017.1393221

Appendix D (i)

Ethics approval letter

THE UNIVERSITY OF SYDNEY

RESEARCH INTEGRITY
& ETHICS ADMINISTRATION

HUMAN RESEARCH ETHICS APPROVAL

The University of Sydney confirms that this project meets the requirements of the National Statement on Ethical Conduct in Human Research.

Project identifier:	2024/HE001170
Project title:	Perspectives of editors of health journals about opportunities and barriers for advancement in the publication of plain language summaries
Application version:	0.03
Chief Investigator:	Dr Danielle Muscat
Project team:	Ms Karen Gainey Professor Kirsten McCaffery
Project start date:	10 Oct 2024
Project end date:	09 Oct 2028
Date of issue:	Thursday, 10 October, 2024

Project summary

We will be conducting semi structured interviews with editors of health and medical journals. Questions will cover aspects of the publication of plain language summaries (PLSs) such as compliance to guidelines, including them in peer review, the use of artificial intelligence (AI) tools and the future of PLSs. PLSs are short summaries of research articles written for a general audience, using plain, easy-to-understanding language. Our previous study involved asking people with chronic illness what they thought about PLS in terms of their use, benefits and how they could be improved. Results suggested that PLSs in their current form do not meet the needs of those who read them. We anticipate that this study will help us gain a better understanding of what changes to PLS that might be possible and an appreciation for any barriers to such change.

Documents approved

Document type	File name	Document version	Application version
Participant Information Statement (PIS)	Appendix 1. Participant Information Statement_V2_29092024.docx	2	0.02
Participant Consent Form (PCF)	Appendix 2. Participant Consent Form_V1_14082024.docx	1	0.01
Recruitment or advertising material	Appendix 3. Recruitment email_V1_14082024.docx	1	0.01
Recruitment or advertising material	Appendix 4. Recruitment email follow up_V2_29092024.docx	2	0.02
Recruitment or advertising material	Appendix 5. Social media advertisement_V1_14082024.docx	1	0.01
Interview or focus group plan	Appendix 6. Interview guide_V3_01102024.docx	3	0.03
Project description / Protocol	Project 4 Ethics Proposal_V2_29092024.doc	2	0.02

Page **1** of **2**

Appendix D (ii)

Interview Guide

Note: This document provides example interview topics and questions that will be addressed. In keeping with qualitative methods, we expect that this topic guide will continually evolve before and during the study in response to emerging learnings. Additional probing questions may be asked to clarify participant responses and ensure understanding.

The interviews will adhere to the following pattern:

1. Introduction
2. Overview of the topic and study rationale
3. Preliminary questions
4. Interview questions

Here is an example of a typical introduction:

Good morning/afternoon. Thank you for taking the time to talk to me about your experience at (insert journal) with plain language summaries, which we define as being short summaries of research articles written for a general audience, using plain, easy-to-understanding language.

I'm Karen Gainey and this study is the final project in my PhD with the Sydney Health Literacy Lab at the University of Sydney. My research involves the use of plain language summaries as a way of communicating health information to a general audience. My previous research has focused on guidelines for writing plain language summaries and understanding what end users of plain language summaries want from them.

You were invited to participate in this study because of your editorial role with (insert journal). I'll be asking you questions to help me understand more about how the editorial process works, particular in relation to plain language summaries and any barriers that might exist to how they are published. Keep in mind that we're just as interested in negative comments about lay summaries and health information as positive comments, and at times the negative comments are the most helpful.

You've probably noticed the 'recording' icon on your screen, so a reminder that we're recording the audio from the session via ZOOM because we don't want to miss any of your comments. We won't be recording any video nor will we be saving the chat transcript. You may be assured of complete confidentiality.

Before we start the interview, I've got a few basic questions to ask to ensure we're talking to a wide range of participants. But before we start, do you have any questions you'd like to ask?

Interview questions

I'd like to understand the factors that impact how decisions are made by health and medical journals that relate to plain language summaries (PLSs). I appreciate that some decisions may be made by the publishing group, rather than each journal, so it would be helpful for me to better understand how the process works.

Decision making and how that could impact changes to PLSs

☐ Can you tell me about your role as a journal editor?

☐ Can you tell me about any experience you have had with PLSs?

☐ When it comes PLSs, who makes decisions about them? e.g., length, content, structure and format (text-based only or graphical/video options)

☐ At what stage of a submission are PLSs required or expected?

☐ Where? i.e., main document or a separate file

☐ Have you faced any barriers to the implementation of PLSs?

☐ Have you received questions from the public or other end-users of PLS about any aspect of their publication?

Mandatory vs optional PLSs

I know from my previous study that PLSs are not mandatory for all journals, so I'd like to explore factors that might have led your journal's decision to make PLSs mandatory or optional.

☐ So I can see that PLSs are ________________for your journal.

☐ What is the reason behind that decision? i.e., what factors were considered?

☐ Does your journal encourage authors to include a PLS even if they are not mandatory?

If so:

- How do you encourage authors to write PLSs?
- Do you think it has increased the number of PLSs submitted?

PLS guidelines

☐ When it comes to guidelines to support authors in writing PLSs, who developed them? Can you tell me a bit about that process?

☐ Was there any end-user input in their development?

☐ When were they last reviewed or updated?

☐ What prompted the revision or update?

PLS audience

☐ What audience(s) do you design your PLSs for and why? i.e., what factors went into the decision.

☐ Is that reflected in your PLS guidelines? i.e., in the PLS guidelines, is it clear who the audience is?

☐ I see the label your journal uses is X. What led to that choice?

☐ What are your thoughts on the impact of the label on the target audience?

PLS guidelines and compliance

My previous project was a study comparing journal guidelines for writing PLSs against PLSs for a number of health and medical journals. We wanted to know if PLSs were written in accordance with the PLS guidelines for the journal in which they were published.

☐ Do you know if anyone has even done this kind of check with the PLSs for your journal to see if they are written according to your PLS guidelines?

☐ If checked, at what stage of submission process and by who? What are the practical barriers to this?

☐ What action, if any, was taken for any non-compliance?

☐ If checked, what items were the most non-compliant?

☐ How important would you rate checking for compliance and why?

Access to PLSs

☐ How are PLSs in your journal made accessible to readers?

☐ What are your thoughts on access to PLSs? e.g., for those articles behind paywalls. What are the barriers and facilitators to access?

☐ What are your thoughts on providing a separate section on your journal website just for PLSs, searchable with keywords? e.g., like the Cochrane Database

☐ Do you think there is any option for implementing that with your journal? Or would that be a decision made at the publishing group level?

PLS and peer review

☐ Are PLSs documents available to peer reviewers?

☐ Are they included formally in the peer review process? i.e., part of a checklist or reporting requirement?

☐ If not, why not? (could be that they are not mandatory for that journal)

☐ If they are included, are there guidelines for peer reviewing PLSs?

☐ Do peer reviewers tend to include PLSs in the report even if not required?

☐ How important would you rate peer reviewing PLSs and why?

Outsourced PLSs

- ☐ Does your journal offer an outsourcing service for PLSs?
- ☐ If so, how popular is this with authors?
- ☐ Do you have any feedback from authors on this service?
- ☐ If not, do you think this would be popular with your journal?
- ☐ Are you aware Wiley offers this service?

PLS formats

- ☐ What formats does your journal offer? i.e., text-based, graphical, video.
- ☐ How popular are each format?
- ☐ Have you had any feedback on the use of non text-based formats?

Use of AI tools

- ☐ What are your thoughts on the use of AI tools for writing PLSs?
- ☐ Does your journal have guidelines for the use of AI in general or PLSs specifically?

Future of PLSs

- ☐ What do you think is the future of PLSs in health and medical publishing?
- ☐ What factors will impact changes to how PLSs are written, published or made available and do you think they will differ to how they are now?

Wrapping up

- ☐ Are there any other barriers or facilitator related to the publication or dissemination of PLSs that you would like to reflect on and share today?
- ☐ Of all the aspects of PLSs we’ve discussed today, which do you think are the most and least important, and why?

Appendix D (iii)

Reporting checklist - Standards for Reporting Qualitative Research (SRQR) *

http://www.equator-network.org/reporting-guidelines/srqr/

Section of manuscript	**Pages.**
Title and abstract	
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	103
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	104
Introduction	
Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	105-106
Purpose or research question - Purpose of the study and specific objectives or questions	106
Methods	
Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	110
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	110
Context - Setting/site and salient contextual factors; rationale**	100
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	107-109
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	106
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	109-110

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection, if/how the instrument(s) changed over the course of the study	109-110
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	111-112
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	109
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	110
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	10
Results/Findings	
Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	113
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	113-131
Discussion	
Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	131-132
Limitations - Trustworthiness and limitations of findings	132
Other	
Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	138
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	138

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien, B.C., Harris, I.B, Beckman, T.J., Reed, D.A, & Cook, D.A. Standards for reporting qualitative research: a synthesis of recommendations. *Academic Medicine*, Vol. 89, No. 9 / Sept 2014 Doi: 10.1097/ACM.0000000000000388. Available from: https://pubmed.ncbi.nlm.nih.gov/24979285/