Dissertation

Publishing health information with options for user-centered customizations (PHOCUS) - Development of a toolbox based on a mixed-methods design

submitted by

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for the academic degree of

Doctor of Medical Science

(Dr. scient. med.)

at the

Medical University of Graz

Institute of General Practice and Evidence-Based Health Services Research

under the supervision of

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2025

Statutory declaration

I hereby declare that this is my original work and that I have fully acknowledged by name all of those individuals and organizations that have contributed to the research for this thesis. Due acknowledgement has been made in the text to all other material used. Throughout this thesis and in all related publications, I followed the "Standards of Good Scientific Practice and Ombuds Committee at the Medical University of Graz".

Graz, 25.05.2025 Cornelia Krenn, BSc, MSc

Disclosure

Parts of this thesis have been published in:

Krenn C[1], Semlitsch T[1], Zipp C[1], Lengauer S[2], Shao L[2,3], Schreck T[2], Bedek M[4], Kupfer C[4], Albert D[4], Kubicek B[4], Siebenhofer A[1,5], Jeitler K[1,6]. (2024). *Customization options in consumer health information materials on type-2 diabetes mellitus-an analysis of modifiable features in different types of media*. Front Public Health; 12:1252244. doi: 10.3389/fpubh.2024.1252244. PMID: 38450136 [1].

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Public presentations on parts of the contents of the dissertation:

Krenn C[1], Semlitsch T[1], Lengauer S[2], Shao L[2,3], Schreck T[2], Bedek M[4], Kupfer C[4], Albert D[4], Kubicek B[4], Siebenhofer A[1,5], Jeitler K[1,6]. (2024). *User-centered customization options in consumer health information materials on type 2 diabetes mellitus*. Poster presentation at the Doctoral Day 2024 at the Medical University of Graz, Austria.

Krenn C[1], Radl-Karimi C[1], Posch N[1], Kubicek B[4], Siebenhofer-Kroitzsch A[1,5]. (2024). *Eine Toolbox zur Erstellung von personalisierten Gesundheitsinformationen*. Oral presentation at the 9. conference of the Austrian Health Literacy Platform, Austria.

All the co-authors have explicitly agreed to use of their published data in this thesis.

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Other publications and presentations related to the research project underlying this dissertation[1]:

Krenn C, Wilfling D, Loder C, Semlitsch T, Jeitler K, Siebenhofer-Kroitzsch A. (2025). *Automated approaches to simplifying complex medical texts for laypersons – A scoping review protocol*. OSF. doi.org/10.17605/OSF.IO/WRB38.

Lengauer S, Proprentner F, Tytarenko M, Krenn C, Jeitler K, Schreck T. (2024). *Automatische Beantwortung von Gesundheitsfragen durch generative KI mittels Retrieval Augmented Generation - Vergleich und Potentiale von Großen Sprachmodellen anhand des Beispiels Diabetes mellitus Typ 2*. Poster presentation at Evidence-based medicine (EbM) congress, Germany.

Tytarenko M, Shao L, Rutar TW, Bedek M, Krenn C, Lengauer S, Schreck T. (2024). *Hierarchical Topic Maps for Visual Exploration and Comparison of Documents*. Presentation at 15th International Workshop on Visual Analytics (EuroVA), Denmark.

Bedek M, Schramm N, Lengauer S, Krenn C, Albert D, Schreck T. (2024). *Analyzing Interactions in an Evidence-based Consumer Health Information System*. Poster presentation at the MIND & BRAIN conference, Austria.

Bedek M, Schramm N, Lengauer S, Krenn C, Albert D, Schreck T. (2024). *Analyzing interactions and processes in an adaptive and evidence-based consumer health information system*. Oral presentation at European Group of Process Tracing Studies (EGPROC), Germany.

Shao L, Lengauer S, Miri H, Bedek M, Kubicek B, Kupfer C, Zangl M, Dienstbier B, Jeitler K, Krenn C, Loder C, Semlitsch T, Zipp C, Albert D, Siebenhofer A, Schreck T. (2023). *Visual Document Exploration with Adaptive Level of Detail: Design, Implementation and Evaluation in the Health Information Domain*. Proceedings of the 18th International Joint Conference on Computer Vision, Imaging and Computer Graphics Theory and Applications, VISIGRAPP, Volume 3: IVAPP, Portugal.

[1] Research project funded by Austrian Science Fund (FWF), FG-11: *"Human-Centered Interactive Adaptive Visual Approaches in High-Quality Health Information"*

Shao L, Lengauer S, Miri H, Bedek M, Kubicek B, Kupfer C, Zangl M, Dienstbier B, Jeitler K, Krenn C, Loder C, Semlitsch T, Zipp C, Albert D, Siebenhofer A, Schreck T. (2023). *Visual Document Exploration with Adaptive Level of Detail*. Oral presentation at the Symposium on Knowledge Spaces & Beyond, Italy.

During the preparation of this thesis “ChatGPT 4” and “DeepL Write” were used in order to improve grammar, readability and writing style of the texts.

Acknowledgements

This dissertation project could not have been completed without the support of many wonderful people. I would like to take this opportunity to express my heartfelt thanks to each of them.

First of all, my sincere thanks go to my supervisor, Univ.-Prof.in Dr.in med. univ. Andrea Siebenhofer-Kroitzsch, MBA. Her constructive feedback, motivational support, and sharing of scientific knowledge were invaluable. Her guidance in keeping the project focused on its core issues provided essential support throughout this period.

A very special thank you goes to my co-supervisor, Dr.in med. univ. Nicole Posch, MPH, for her uncomplicated support, positive attitude and for always having an open ear for me throughout this dissertation project.

Another thanks go to my second co-supervisor, Univ.-Prof.in MMaga. Dr.in phil. Bettina Kubicek, and my wonderful colleague Christina Radl-Karimi, PhD, for their valuable support during the qualitative research phase of this project. Their contributions were immensely helpful.

I would also like to thank Sen. Scientist Dr. med. univ. Klaus Jeitler for his support in the conceptualization of the thesis topic and the publication of the paper.

I am particularly grateful to my wonderful colleague Mag.a (FH) Christine Loder, MPH for supporting me emotionally and for strengthening my confidence in myself and my abilities.

Special thanks go to the amazing ladies of Herzbergwerk. Our band rehearsals, gigs, and precious time spent together, laughing and making music were a vital source of energy and provided the perfect balance to the work on this dissertation.

A heartfelt thank you goes to my partner Markus for his understanding and patience, especially during the many weekends I spent working on this thesis and for lovingly cooking the most delicious food to keep me energized on all those days.

My deepest gratitude goes to my parents. Their unending love, even during times when I was busy and had little time to spare, has truly been my lifelong foundation. They have shaped me, supported me through challenges, patiently stood by my side, and always believed in me.

The doctoral candidate received funding from the Austrian Science Fund FWF (FG 11) and the Medical University of Graz through the Doctoral School “Sustainable Health Research.

Table of Contents

List of abbreviations

AI	Artificial intelligence
CHI	Consumer health information
CHIM	Consumer health information material
COREQ	Consolidated criteria for reporting qualitative research
DiGAS	Digitale Gesundheitsanwendungen
DO	Diabetes organization
EIDM	Evidence-informed decision-making
FWF	Fonds zur Förderung der wissenschaftlichen Forschung (Austrian Science Fund)
IP	Interview partner
IPDAS	International Patient Decision Aid Standards
LLM	Large Language Model
MN	Marginally new
na	Not applicable
NNT	Number needed to treat
NNS	Number needed to screen
NNH	Number needed to harm
OO	Other organization
p-HI	Printed or printable health information
PIAAC	Programme for the International Assessment of Adult Competencies
T2DM	Type 2 diabetes mellitus
WCAG	Web content accessibility guidelines
WDO	Websites of diabetes organization
WOO	Websites of other organization

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Zusammenfassung

Hintergrund: Informierte Entscheidungen im Gesundheitsbereich erfordern das Verstehen von Gesundheitsinformationen (GI). Die Erstellung verständlicher GI kann jedoch herausfordernd sein, da Herausgeber*innen von GI unterschiedliche kognitive Fähigkeiten, Gesundheitszustände, Vorwissen und Präferenzen von Nutzer*innen berücksichtigen müssen. Ziel dieser Thesis war die Entwicklung einer Toolbox, die Herausgeber*innen von GI über verschiedene Anpassungsmöglichkeiten zur Implementierung informiert, um den Nutzer*innen schließlich eine Auswahl dieser Optionen zu ermöglichen.

Methodik: Die Entwicklung der Toolbox folgte einem dreiphasigen Mixed-Methods Ansatz, der quantitative und qualitative Methoden kombinierte. Phase 1 (Exploration), umfasste einen State-of-the-art Review, einschließlich einer Häufigkeits- und Vergleichsanalyse verfügbarer Anpassungsoptionen in verschiedenen Medientypen von GI zu Diabetes mellitus Typ 2. Zusätzlich wurde eine ergänzende Analyse auf Webseiten durchgeführt. In Phase 2 (Konzeptualisierung) wurde eine vorläufige Toolbox entwickelt, die in einem Reflexionsworkshop mit Expert*innen für Gesundheitskompetenz und -kommunikation diskutiert und kritisch weiterentwickelt wurde. Zuletzt wurden leitfadengestützte, halbstrukturierte Interviews mit Herausgeber*innen von GI geführt, um Herausforderungen bei der Umsetzung von Anpassungsoptionen und Erwartungen an die finale Toolbox zu ermitteln. In Phase 3 (Finalisierung) wurden alle Daten aus Phase 1 und 2 zusammengeführt.

Ergebnisse: Der State-of-the-art Review (Phase 1, 04/2021-05/2022) ergab 24 verschiedene nutzerzentrierte Anpassungsoptionen in 114 GI, von denen die Mehrheit (65%) keine Möglichkeit anbot den medizinischen Inhalt oder die Darstellungsart anzupassen. Im Reflexionsworkshop (Phase 2, 03/2024) wurden sechs zusätzliche Anpassungsoptionen identifiziert, während die Interviews mit Expert*innen (Phase 2, 04-05/2024) neun weitere Optionen hervorbrachten. Die Interviews betonten die Relevanz der Integration zielgruppenspezifischer Bedürfnisse sowie die Notwendigkeit einer praktikablen und benutzerfreundlichen Gestaltung der Toolbox. Die neu entwickelte Toolbox PHOCUS wurde in einem Zeitraum von sechs Monaten finalisiert und gliedert die Optionen in drei Kategorien: (1) Sprache, (2) Darstellungsarten und (3) Barrierefreiheit von Webinhalten. Die finale Toolbox bietet Praxisbeispiele und konkrete Implementierungstipps für Herausgeber*innen von GI.

Diskussion: Die Toolbox ist als dynamisches Instrument konzipiert. Sie wird kontinuierlich um neue Anpassungsoptionen ergänzt und weiterentwickelt, um sowohl neuen wissenschaftlichen Erkenntnissen als auch sich ändernden Bedürfnissen von Nutzer*innen zu entsprechen. Die nächsten Schritte sind die Toolbox über Publikationen und Workshops zu disseminieren, um eine breite Nutzung durch Herausgeber*innen von GI sicherzustellen.

Abstract

Background: The understanding of health-related information is essential for making informed decisions. However, the development of understandable consumer health information (CHI) can be challenging as publishers of CHI need to consider various cognitive abilities, health conditions, prior knowledge, and personal preferences of consumers. The aim of this thesis was to develop a toolbox to inform publishers of CHI about various customization options for implementation, ultimately allowing consumers to select from these options.

Methods: The development of the toolbox was based on a three-phase mixed-methods approach, combining both quantitative and qualitative methods. Phase 1 (exploration) involved a state-of-the-art review, including a frequency and comparative analysis of available customization options in various media types of CHI for diabetes mellitus type 2. In addition, an extended analysis to identify further customizations was conducted on websites. In phase 2 (conceptualization), a preliminary toolbox was developed and then critically refined through a workshop with experts in health literacy and health communication. Finally, guideline-based, semi-structured expert interviews were conducted with publishers of CHI to determine challenges in implementing customization options and expectations for the final toolbox. Phase 3 (finalization) involved synthesizing all data from phase 1 and 2.

Results: The state-of-the-art review (phase 1, 04/2021-05/2022) identified 24 different user-centered customization options in a representative sample of 114 CHI. However, the majority (65%) of CHI did not offer any possibility to customize the medical content or the type of presentation. The reflection workshop (phase 2, 03/2024) identified additional six customization options, while the expert interviews (phase 2, 04-05/2024) revealed nine more. The expert interviews emphasized the necessity of a practicable and user-friendly design of the toolbox. Furthermore, the integration of target group-specific needs was emphasized. The newly developed toolbox, named PHOCUS (**p**ublishing **h**ealth information with **o**ptions for user-centered **cus**tomizations), was finalized over six months and comprises three main categories of user-centered customization options: (1) language customizations, (2) presentation customizations, and (3) web content accessibility customizations. The final toolbox provides a variety of examples of customization options and offers key considerations for publishers of CHI when implementing these options.

Discussion: The toolbox is designed as a dynamic instrument. It is continuously updated and further developed with new user-centered customization options to align with emerging scientific evidence and changing consumer needs. Further steps include the dissemination of the toolbox through publications and workshops to ensure its broad use by publishers of CHI.

Introduction

Health communication

Communication plays a crucial role in what and how people think, feel, know and make decisions about their health. The way and medium through which communication occurs can vary significantly, ranging from conscious to unconscious, verbal to non-verbal, and from direct interactions (e.g., in interpersonal doctor-patient conversations) to more technical or media-based channels (e.g., via social media, telephone, brochures, information campaigns). Moreover, communication is not simply a one-sided process, but a mutual interaction. The information exchanged is encoded by the sender in a specific form (e.g., through language, signs or symbols) and has to be decoded by the receiver. If there is no common repertoire of signs and symbols, or if the information is transmitted incorrectly, misunderstandings are inevitable [2-4]. In general, communication is a complex process with several influencing factors: (i) characteristics of the sender (e.g., credibility, status, sympathy, presumed motives), (ii) characteristics of the transmission method (e.g., oral/personal, written, digital, visual), (iii) reception situation (e.g., undisturbed environment, presence of other people), (iv) characteristics of the message (e.g., factual content, emotional tone, visual design, level of language and content), and (v) characteristics of the recipients (e.g., emotional state, motives, values and behavior). The process of the information acquisition comprises two main steps: draw attention to the message and process the content of the message. This processing can trigger both cognitive (e.g., understanding arguments or assessing credibility) and emotional reactions (e.g., satisfaction, concerns or anxiety). This can lead to changes in the knowledge, attitudes or behavior of the recipient. Such changes can be in- or unintentional as well as short or long-term [3, 5].

The main objective of health communication is to inform and educate individuals and the general public about health-related issues. In particular, health communication should support people in making informed decisions about treatment options and promote health-conscious social norms. Furthermore, it should raise awareness of health risks and provide both motivation and skills needed to minimize these risks. Additionally, health communication can increase the demand for health services and drive political and social change [6]. Effective health communication can result in improved treatment outcomes, greater adherence to treatment schedules, higher patient satisfaction, and increased motivation to adopt or maintain healthy behaviors and actively self-manage their conditions. Furthermore, it has been shown to reduce stress and anxiety, improve quality of life, and strengthen the overall health literacy of the population [7-9].

Health communication synthesizes expertise from various disciplines including communication, social and natural sciences, as well as medicine and public health. Research and practice of health communication can be organized into five major interrelated areas: (1) Communication in the delivery of care, (2) Communication and health promotion, (3) Health risk communication, (4) E-health communication, and (5) Communication in managing health care systems [10].

In this thesis, the term health communication is understood according to the definition by the Society of Health Communication (SHC), which defines health communication as "*the science and art of using communication to advance the health and well-being of people and populations. Health communication is a multidisciplinary field of study and practice that applies communication evidence, strategy, theory, and creativity to promote behaviors, policies, and practices that advance the health and well-being of people and populations."* [11]

Health literacy

While health communication plays a key role in conveying information and raising awareness of health issues, health literacy is the ability of individuals to understand and process this information into practical health decisions [12, 13].

Health literacy encompasses people's knowledge, motivation, and abilities to find, understand, evaluate and apply relevant health information in everyday life in order to make decisions in the areas of health promotion (to maintain and strengthen health), prevention (to prevent complaints or diseases), and disease management (for existing health problems or diseases) that maintain or improve their health and quality of life [14].

Health literacy forms the foundation for individuals to understand and critically evaluate health information, ultimately enabling them to make informed health-related decisions independently [15].

According to this definition, health literacy goes beyond simply reading of health information and following medical instructions. To be health literate, people need various skills, including reading and understanding texts as well as locating and interpreting information in documents (print literacy), dealing with quantitative data (numeracy) and the ability to communicate effectively, both through speaking and active listening (oral literacy) [16, 17].

Furthermore, health literacy is a dynamic concept that depends on both individual skills and structures and processes in organizations and health systems that facilitate the access and the use of consumer health information (CHI) [18]. A key determinant of strengthening the health literacy of the community is therefore the design and organization of the health care system itself [19].

Individuals with inadequate health literacy tend to have lower levels of health-promoting physical activity and dietary behavior, higher body mass index, and poorer perceptions of their health situation. They are more likely to have chronic illnesses and health problems that impair their daily lives, have more difficulties in managing chronic illnesses, and use the healthcare system more intensively through more visits to general practitioners and specialists, outpatient care, emergency services and longer periods of sick leave. Furthermore, limited health literacy is associated with high risk of mortality, health disparities and increased costs in the health care system [20-25].

In contrast, research has shown that people with higher levels of health literacy have more trust in physicians and in the health care system [26]. Health literacy is of particular significance in the context of disease prevention and management, given its capacity to contribute to the reduction of inequalities in disease burden and mortality [27, 28].

The development of health literacy can be influenced by many factors. At an individual level, factors such as a low level of education, a lack of literacy skills, limited language skills (e.g., due to migration), limited cognitive abilities (e.g., due to age or illness), a lack of basic health knowledge, and cultural differences in the perception of health or psychosocial burdens (e.g., stress, anxiety, mental illness) can be obstacles. At a systemic and structural level, health information that is too complex (e.g., an overload of medical terminology or texts that are difficult to understand), a lack of accessible information (e.g., easy language or visual support), limited access to digital resources and a communication style that is not appropriate for laypeople can all contribute to limiting health literacy. Furthermore, a number of external factors have been identified as having the potential to exert a detrimental effect on health literacy. These factors include socio-economic conditions, such as poverty and unemployment, limited access to education and health information, technological developments, such as the digital divide, and the spread of misinformation and disinformation, particularly via social media [29-40].

The Austrian Health Literacy Survey (HLS19-AT) from 2020 reveals that Austria has considerable work to undertake to enhance the health literacy of the population in comparison to seven other European countries. The findings of the survey indicate that enhancements are particularly imperative in the domains of information management, health promotion, and the evaluation and utilization of CHI. Challenges are observed in navigation skills/orientation within the healthcare system and digital health literacy/use of online information. The survey further reveals that individuals with a primary school leaving certificate, those experiencing financial precariousness, and those confronted with chronic illnesses and health problems exhibit lower levels of self-assessed health literacy [22].

The importance of evidence-based health information

At the time of writing the thesis, there was no universally recognized definition of the term CHI available. However, there are several similar descriptions that outline the term [41-44]. For this thesis, the author used following definition of CHI: *"CHI is intended for potential or current users of medical services. It is designed to be educational, and can help individuals make decisions about health-related behavior and medical treatments. CHI may include resources about prevention, self-care and wellness, diseases and conditions, treatment, health care options, and more. It differs from clinical information - that is, information written by and for medical professionals - in that it is developed with the layperson in mind, involving less technical language and more user-friendly formats."* [45]

However, it is crucial to provide patients with high-quality CHI to ensure informed decision-making [46]. A reliable foundation for informed health decisions are evidence-based health information. Evidence-based health information provide comprehensive, understandable, transparent, unbiased, and objective information that is relevant to health decisions. They include information on the progression and impact of diseases, measures for health maintenance (prevention and health promotion), early detection, diagnostics, treatment, palliation, rehabilitation, aftercare, nursing, or coping with illness. The benefits and harms of interventions are presented based on patient-relevant outcome parameters such as mortality, morbidity, and health-related quality of life. Evidence-based health information are created based on a transparent methodological approach [47-49].

Evidence-based health information can support patients to understand their conditions, realistically assess the benefits and harms of treatment options, manage their health in everyday life, and actively engage in self-care management [46].
However, during the development process of evidence-based health information publishers of CHI have to fulfil many requirements, such as (1) the identification of specific information needs of consumers, including customizations to complexity, medical content, language, and skills of target groups (2) the systematic search for evidence, (3) the informed selection of appropriate evidence, (4) the unbiased presentation of relevant research results, e.g., data on mortality, morbidity and health-related quality of life, (5) the appropriate presentation of comparative interventions, e.g., placebo or another treatment option, (6) the optimal communication of risks and uncertainties, (7) the consideration of age and gender differences, and (8) the transparent disclosures of authors and publishers [47].

In line with these principles, evidence-informed decision-making (EIDM) is defined as a process that emphasizes that decisions should be informed by the best available evidence from research, while also considering other key factors such as context, public opinion, equity, feasibility of implementation, affordability, sustainability, and acceptability to stakeholders [50-52]. EIDM is a transparent methodology that relies on a structured and consistent set of steps to systematically find, assess the quality of, and apply evidence [51].

Subsequently, evidence-based practice can help to reduce health inequalities and support national goals such as the promotion of patient-centered care, including equal access to treatment and the reduction of misinformation. These aspects are crucial for improving the quality of health care and strengthening public trust in the health care system [47, 53].

Limitations and barriers of currently available CHI

Although EIDM relies on high-quality, evidence-based health information as a key foundation for making better, more transparent decisions that improve healthcare outcomes [54, 55], the currently available CHI are often limited by various barriers that hinder people's ability to find, assess, and apply it effectively in practice.

Information overload

The flood of information is a key challenge that has been exacerbated in the modern knowledge and information society, particularly through the Internet. Consumers are confronted with a variety of choices, whether for health advice, medical devices or treatment options. Both the quantity and complexity of available information can easily lead to an overload, especially when making decisions about one's own health or that of family members [22, 56]. During the Covid-19 pandemic, this effect was exacerbated in the form of an "infodemic": the population was confronted with inconsistent and inaccurate information, leading to uncertainty and fear, especially among the elderly [57, 58]. Research demonstrated that factors such as low education level, low health literacy, poor searching skills, greater concern about the quality of information, low socioeconomic status and ethnicity, trait anxiety, older age and lower confidence in seeking health information can increase the risk of information overload [59].

Different information needs of target groups

Consumers of health information differ not only in their levels of knowledge, skills and personal characteristics, but also in their individual information needs. Information needs are a dynamic concept that should be understood as a cognitive, social, cultural and historical phenomenon. Information needs are significantly influenced by a variety of contextual and situational factors, resulting in different capabilities to find, comprehend, process and use health information. In addition, emotional factors play a significant role, as uncertainties, emotional coping and interpersonal needs influence individual behavior when searching for and using CHI [60].

Specifically, people are confronted with different everyday and health problems. For example, socially disadvantaged families and single parents are confronted with health problems such as allergies, obesity, attention deficit hyperactivity disorder, depression or addictive disorders. This is often compounded by relationship problems and financial worries. Parents are often worried about their children's health, but less so about their own. They find it difficult and stressful to distinguish between harmless symptoms and serious health problems, and worry about missing important warning signs. Discussions about controversial topics such as vaccinations increase uncertainty, as does unsolicited advice from institutions. For mild symptoms, they often seek advice from family and friends and act proactively, while for more severe symptoms, especially in children, they seek medical help [61]. However, medical explanations are often perceived as inadequate, leading to additional search for information in digital media [61].

In contrast to socially disadvantaged families, the daily lives of older people are often quiet and full of leisure activities. However, illness is increasingly impacting their lives and is a major burden, whether through chronic conditions or acute problems such as falls. Preventing further illness is important to many. In their free time, older people often look after themselves and others. Their health is a central topic of conversation and there is a strong need to communicate. They try to stay in control of their health and are particularly interested in new treatments, ways to avoid aggravation and late effects, and the experiences of others with similar health problems. After visits to the doctor, they often do their own research to better understand the information they have received, suggesting that their information needs have not been adequately met. They often seek second and third opinions, not only from doctors, but also from family, friends and other people affected [61].

The research about information needs has increased steadily in the last decades. However, the operationalization of information needs is still limited. It assumes that people are able to recognize and clearly articulate their information needs – an ability that is often lacking, especially in people with inadequate health literacy, limited disease experience or poor access

to information. Further, studies often do not support consumers' ability to articulate their needs precisely, as studies often use predetermined choices of information needs [60].

Different preferences of media types

Information channels play a central role in health communication, as they have a significant impact on access to knowledge and dissemination of CHI. However, the information-seeking behavior and used information channels have changed significantly over time due to technical, social and cultural developments. Whereas in the past, personal conversations between health professionals and patients or their relatives, printed media and radio dominated, nowadays digital media such as online health portals, mobile apps and social networks play a central role in health communication. All information channels have their specific advantages: Mass media such as television, radio and print media continue to reach a broad audience and remain an important part of health communication. On the other hand, digital media enable interactive and sometimes personalized access to information. Face-to-face communication (e.g., doctor-patient conversations, networks of family and friends, self-help groups) remains essential to explain complex issues, develop individual treatment plans and share experiences with others affected. In addition, public campaigns and targeted information materials supplement the effective dissemination of CHI. The preference of specific types of media and formats depend on factors such as age, technological affinity, accessibility and situational circumstances [62-70].

Younger people often prefer digital platforms such as Instagram and YouTube, which allow a dynamic exchange of information through multimedia content and interactive elements. Health information in fictional entertainment programs ("entertainment-education") had short-term effects on health knowledge, but has also proved successful for younger and hard-to-reach target groups [66, 71]. Older people often prefer printed materials such as brochures and flyers, while socially disadvantaged families use both analogue and digital sources of information [61]. Migrants and refugees often use information sources from their home countries or networks within their communities [57]. Mobile apps are becoming increasingly important for self-management of diseases, for example through functions such as medication reminders or health monitoring [72].

Nevertheless, physicians are the primary source of health information for patients. However, physicians often lack the time to answer all of their patients' questions comprehensively. This gap leads many people to search for answers themselves. However, they often come across content that is either difficult to access or not tailored to their individual needs [73-75]. In the medical practice, physicians provide patients with both analogue and digital information for

them to take home. Printed materials are given to patients by 89% of physicians. At the same time, 53,8% of physicians recommend digital information sources for further research [76].

Language barriers and different levels of understanding

People have different levels of language skills, which are influenced by various factors such as education, background, and individual skills. Research has demonstrated that language barriers can negatively impact on various domains, for example the management of chronic diseases, the provision of palliative care, and the management of pain [77-81].

While some people are able to understand and process complex information [82], other people find it difficult to grasp specialized medical terms or complex sentence structures and prefer clear and concise health information in an easy-to-understand language [74, 83]. A national survey in Germany of the health information seeking behavior revealed that 22,9% of the respondents found health information difficult to understand [73]. Furthermore, the mathematical skills of some target groups may be deficient, resulting in challenges in comprehending numerical data and probabilities [84]. According to the Programme for the International Assessment of Adult Competencies (PIAAC) study 2023 in Germany, less than 50% of people without a school-leaving qualification are competent in performing rudimentary arithmetic operations, understanding simple percentages, and identifying components in familiar graphic or spatial representation. Their mathematical skills do not extend beyond these fundamental operations [85].

However, over time, consumers of health information become more familiar with medical vocabulary as they become more intensively involved with their diagnosis [86]. However, most CHI is designed for people with higher levels of literacy and readability [87].

For socially disadvantaged families and older people, it is recommended that benefits and harms of treatment options, causes and course of diseases and information about the healthcare system should be written as simple as possible [61]. Muscat et al. (2021) determined that only 12% of patient decision aids were tailored to disadvantaged groups, i.e. people with lower literacy, health literacy or numeracy, people with a lower level of education or socioeconomic status, people who are uninsured, people with language barriers and people who are socially disadvantaged because of their ethnicity or race or who are medically underserved. The researchers did not identify any patient decision aids written at a sixth-grade level or below. In addition, only 40% of the decision aids analyzed were understandable and only 20% were designed to be practical for the target group [88].

Linguistic minority groups, like deaf and hard-of-hearing people, face different communication and language barriers leading to an inaccessibility to CHI and consequently resulting in a

generally low health knowledge level and limited health literacy compared to hearing individuals [89-92].

Culturally and linguistically diverse people demonstrate a preference for multilingual CHI to facilitate more effective understanding of health-related content. It is recommended that CHI be formulated in a culturally sensitive and inclusive language to address the needs of this special target group [93, 94].

People with complex diseases are often confronted with inconsistent, incomplete or complex information, which can lead to confusion and overload. This can make it difficult for them to actively self-manage their disease [95].

Mobile apps, such as those for cancer, are often written in a language that requires a high level of education. However, only few of these apps are suitable for people with lower literacy levels. Similarly, patient guidelines are often not adapted to the language level of the general population, because they are too complex and require some statistical knowledge [83, 96].

Different preferences in types of presentation

Data visualization plays a central role in the communication of health information, as they can present complex content in a clear and understandable way. Diagrams, infographics, pictograms and illustrations are effective ways of visualizing health information. However, people's preferences and abilities to understand visual representations vary widely [75]. While some people can easily interpret abstract graphs and statistics, others prefer simpler visualizations. Inappropriate or difficult-to-understand visualization can lead to important information being missed or even misinterpreted [76]. For example, socially disadvantaged families prefer digital CHI with playful elements (e.g., tests or quiz), information portals with easy registration and secured data protection as well as explanatory images [61]. Furthermore, for culturally and linguistic diverse people, visual presentations such as images and diagrams are useful to overcome language barriers [94].

Different preferences of depth of information

The depth of information in CHI refers to the level of detail and complexity of the medical content. At the beginning of an illness, the need for information is usually particularly high because the disease is new and unknown. During this phase, people search intensively for information to learn more about the disease and reduce their uncertainty. Over time, the need for information tends to decrease, although it may increase again when unexpected or new medical events occur [86].

With regard to information channels, the depth of information on social platforms such as Facebook is limited compared to CHI on websites, partly due to space constraints. However,

users of social media platforms expressed a need for more specific and practical information on social platforms to facilitate the self-management of their diseases [74]. Even more, complex health issues require detailed and well-prepared health information [96]. Older people generally prefer compact information, but show a greater interest in more detailed content for more complex topics [61].

Different accessibility requirements for digital health information

Publishers of CHI face the challenge of preparing digital CHI that are accessible to several target groups of CHI. Digital CHI are often not sufficiently accessible to people with physical, cognitive or language impairments. In particular, older people and those with limited access to digital technology experience different challenges when consuming digital CHI. Despite the existence of guidelines for the accessible design of web content (WCAG), these requirements are often not implemented [97-99].

Statically approaches in the development of CHI

Although the development of high-quality, evidence-based health information requires an assessment of the information needs of the target groups, the process of developing CHI usually follows a rigid, non-individualized approach, providing consumers with mainly the same content in terms of language, presentation, and depth of information ("one-size-fits-all design"). This can make it difficult for certain target groups to understand and use the information. Particularly vulnerable groups, such as older people, people with low levels of education or people with a migration background, require specific user-centered customizations in terms of language or presentation to meet their individual needs [100-102].

Personalization approaches for CHI

As populations become more diverse, the need to provide personalized CHI has emerged as a pressing challenge for health policy-makers and information providers worldwide [103, 104]. The Covid-19 pandemic has highlighted the importance of clear, specific, unambiguous, and tailored evidence-based CHI for an effective health communication [57, 58]. Personalized CHI has the potential to improve general health literacy, and to strengthen users' perceptions of usefulness and personal relevance. These factors are closely linked to increased motivation for behavioral change and the development of sustained, health-promoting attitudes [105]. However, the provision of personalized information materials has rarely been offered so far [76]. Societal changes such as demographic shifts towards an ageing population, changing trends, pandemics, increasing digitalization, information overload, and rising health care costs

complicate the development of high-quality, evidence-based CHI in an increasingly dynamic and complex society [106, 107].

Publishers of CHI face many challenges in customizing health information to the different information needs and personal capabilities of consumers. In order to facilitate the provision of user-centered CHI, there is a necessity for the development of novel approaches to the creation of such information [56, 76, 88]. Moreover, the development of user-centered CHI requires that publishers of CHI possess a deep understanding of the preferences and needs of their target audiences [75, 108]. In addition to the publishers' expertise in knowing and understanding audience needs, flexible health information systems are required to ensure that the information is kept up to date [56].

Research gaps

Well-established guidelines exist to support the development of high-quality health information. Internationally, the International Patient Decision Aid Standards (IPDAS) collaboration, for instance, provides a crucial set of criteria for the development and evaluation of patient decision aids [109]. In the German-speaking area, guidelines such as "*Gute Praxis Gesundheitsinformation*" [48] and „*Leitlinie evidenzbasierte Gesundheitsinformation*" [110] serve as a guide for publishers for the development of high-quality, evidence-based health information.

However, there is still an absence of supporting guidance or tools for publishers in the case of implementing user-centered customization options in CHI depending on the different needs of target groups, indicating a research gap in this area.

Furthermore, at the time of writing the thesis, no study has investigated whether and what kind of user-centered customization options are currently available in different media types of consumer health information materials (CHIMs), indicating a further research gap in this area.

Consequently, there is an urgent need to provide an overview of user-centered customization options for publishers of CHI, and to provide clear recommendations for publishers on how these user-centered customization options can be effectively implemented in CHI.

Research project "*Human-Centered Interactive Adaptive Visual Approaches in High-Quality Health Information*"

This dissertation thesis is embedded in the research project *"Human-Centered Interactive Adaptive Visual Approaches in High-Quality Health Information"* (FG-11), funded by the Austrian Science Fund (FWF). The name of the information system is A+CHIS (stands for advanced interactive, adaptive, personalized and visual consumer health information system).

The aim of this research project is the development of a novel and innovative visual health information system, based on the idea of adaptive, interactive document and information visualizations. The project will develop new concepts that integrate evidence-based medical knowledge, cognitive-psychological mechanisms, and innovative interactive data visualizations, customizing to individual health information requirements. These concepts will be operationalized within a testbed system focusing on case scenarios of diabetes mellitus type 2 (T2DM). The decision to focus on T2DM was underpinned by the understanding that the condition is characterized by its complexity and the dynamic nature of its progression. This, in turn gives rise to a changing array of information requirements for patients. However, it is noteworthy that the fundamental results of this project have the potential to be used to other medical information cases as well.

The research project is an interdisciplinary cooperation project between the Institute of Computer Graphics and Knowledge Visualization (Graz University of Technology), the Institute of Psychology (University of Graz), and the Institute of General Practice and Evidence-based Health Services Research (Medical University of Graz).

1.1. Aim of the thesis

This thesis was guided by two aims:

The primary aim of this thesis was to develop PHOCUS (**p**ublishing **h**ealth information with **o**ptions for user-centered **cus**tomizations), a toolbox designed to provide publishers of CHI with a comprehensive overview of user-centered customization options suitable for implementation in health information materials.
The overarching aim is that publishers of CHI offer consumers of health information different customization options, allowing them to select the customizations that best suit their needs and preferences in order to receive individually tailored health information.

The secondary aim of this thesis was to analyze different media types of currently available CHI regarding their potential for user customization. A comparative analysis of the various media types was conducted to identify similarities and differences of customization options.

1.2. Research questions

The following research questions were formulated in accordance with the aims of this thesis:

Research Question 1:

- To what extent do existing CHIMs about T2DM across different media types enable consumers of CHI to individually select or pre-select content based on their specific situations and needs?

Research Question 2:

- What similarities and differences exist between the identified user-centered customization options across different media types of CHIMs on T2DM?

Research Question 3:

- How should the content, design, and structure of a toolbox with user-centered customization options be developed to effectively support publishers of CHI in implementing these options in practice?

2. Methods

The toolbox PHOCUS was developed through a multi-stage, mixed-methods approach, combining both qualitative and quantitative methods. This approach ensured a systematic and practice-oriented development by incorporating diverse perspectives and data sources of customization options in CHI. The process was iterative, facilitating continuous refinement of the toolbox. The development process consisted of three phases with a total of seven steps, as illustrated in Figure 1.

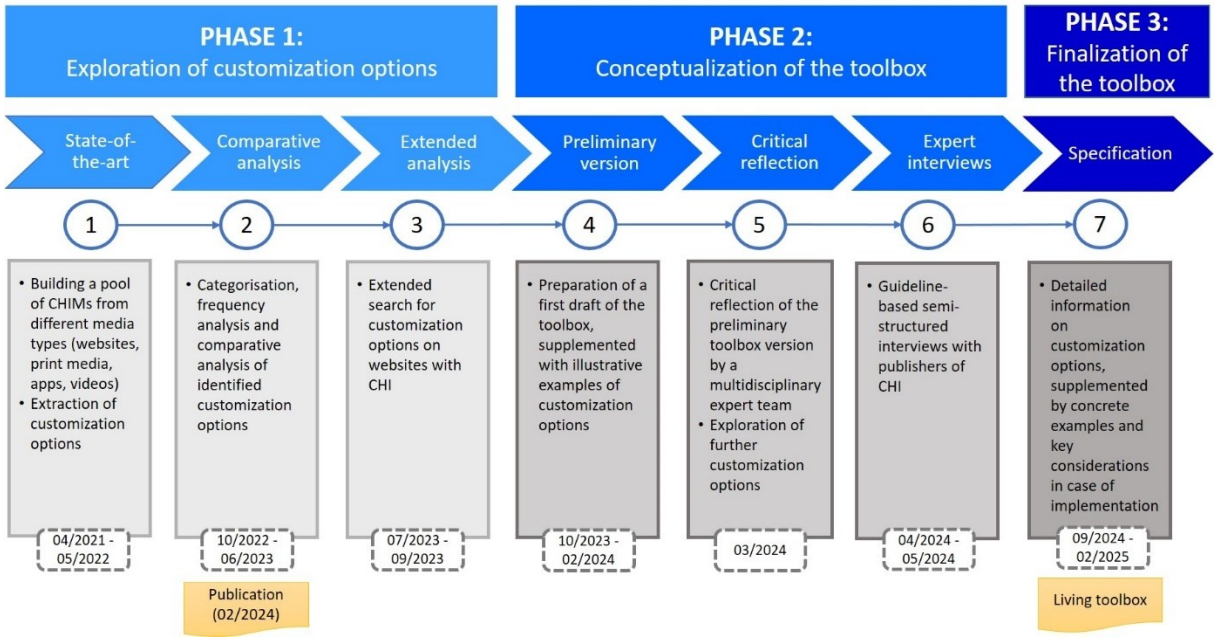


Figure 1: Development process of the toolbox

2.1. Exploration of customization options (Phase 1)

2.1.1. State-of-the-art review of customization options

The initial step in investigating user-centered customization options in CHI was to build a pool of CHIMs across different media types. From this pool, a representative sample was selected, which served as the basis for identifying and analyzing the customization options currently available.

Search strategy

A focused search of diverse media types of CHIMs was conducted, focusing on type 2 diabetes mellitus (T2DM). T2DM was selected as the focus of this project due to its high prevalence, the complexity of its management, and the significant impact of lifestyle factors, all of which necessitate tailored information for effective self-care. It was hypothesized that consumer's information needs change as the disease progresses [1].

An extensive search strategy, conducted between April 2021 and May 2022, was used to identify relevant CHIMs for T2DM (Table 1) [1]:

Table 1: Search strategy of customization options

①	**Targeted website search** Websites from established health information publishers, including diabetes associations (both national and those listed by the International Diabetes Federation), national health portals, health ministry websites, and reputable international health information providers, were examined to retrieve relevant CHI. Additionally, relevant printed or printable health information (p-HI), videos, and apps were collected from these websites.
②	**General website search** To identify further relevant websites, p-HI, videos, and apps, a targeted Google search was also performed.
③	**Mobile app search** Systematic searches of the Google Play Store (Android) and the App Store (iOS) were conducted to identify relevant apps providing CHI. These searches used both English and German search terms, including 'diabetes mellitus type 2', 'diabetes typ 2', 'typ II diabetes', 'type-2-diabetes', 'Diabetes mellitus', 'DM Typ 2', 'Typ-2-Diabetes', 'Typ-2-Diabetiker', 'Altersdiabetes', 'adult-onset diabetes', 'Zuckerkrankheit', and 'Nicht-insulinabhängiger Diabetes mellitus'.
④	**Video search** Videos were sourced from the websites identified in steps 1 and 2, and supplemented through a targeted search on the streaming platform YouTube using the same search terms as those employed for the mobile app search.
⑤	**Bibliographic database search** Moreover, a comprehensive search was conducted in the bibliographic database PubMed to identify scientific papers mentioning relevant CHIMs on T2DM. The detailed search strategy is provided in *Appendix 1*.
⑥	**Local search** Using in-person visits or email communication, a local search for CHIMs was conducted across diabetes outpatient clinics, primary healthcare units, T2DM self-help groups, pharmacies, and practices linked to an internal research and teaching network of the author's affiliated institute of the Medical University of Graz.

Eligibility criteria

The selection of CHIMs followed the criteria defined in Table 2 [1].

Table 2: Eligibility criteria for CHIMs on T2DM

	Inclusion criteria	Exclusion criteria
Type of media and information material	Digital and print/printable media, such as websites, apps, videos, brochures, leaflets, folders, posters, patient guidelines, fact sheets and decision aids	Blogs, info terminals, books, press releases, podcasts, social media posts, online forums, radio/TV programs, scientific papers, patient biographies, general population educational material, and materials designed for health professionals (e.g. clinical guidelines)
Content of information material	Information materials addressing general information on T2DM, such as symptoms, diagnosis, pharmacological and non-pharmacological treatment options, self-management, prevention and complications	Information materials primarily focusing on the use of disease-related assistive technologies (e.g. instructions for blood glucose measurement, insulin pumps, etc.)
Target group	CHIMs targeting patients with T2DM (regardless of age, gender or social group), their relatives, or individuals interested in T2DM	CHIMs targeting patients with prediabetes, diabetes mellitus type 1, late autoimmune diabetes in adults, maturity onset diabetes of the young, other rare types of diabetes, or gestational diabetes
Language	CHIMs published in German or English	CHIMs published in languages other than German or English
Geographic area	CHIMs published in middle- and high-income countries, based on the World Health Organization mortality strata classification [111]	CHIMs published in low-income countries, based on the World Health Organization mortality strata classification [111]

Selection of a representative sample

In order to ensure generalizability and external validity of the analysis, a representative sample of CHIMs was selected from the previously compiled pool, ensuring an efficient analysis while minimizing selection bias. Given the potential influence of media type and publisher on the presence and nature of customization options, the sample was balanced through block randomization, ensuring equal representation across different media types and publishers organization. The block randomization was performed using a random number generator in Microsoft Excel. The block randomization resulted in six groups: (1) Websites of diabetes organizations (WDO), (2) Other websites not specialized in diabetes (WOO), (3) p-HI from diabetes organizations (p-HI DO), (4) p-HI from other organizations (p-HI OO), (5) Apps, and (6) Videos. Each block contained six CHIMs, with one CHIM randomly selected from each of the six pre-defined groups [1].

Data extraction

The data extraction process was principally guided by preliminary considerations outlining following potential customization options [1]:

- Medical content, e.g., relevant subfield of diabetes, general or specific information
- Type of presentation, e.g., running text, graphic, table, interactive visualization
- Level of detail of information, e.g., depth and complexity of medical content
- Sociodemographic customization, e.g., age, gender, education or ethnicity
- Language customization, e.g., translation of medical content in additional languages
- Technical customization, e.g., font style, font size, font color
- Situational customization, e.g., current health status, current therapeutic situation

However, an open-minded approach was used throughout the data extraction process, allowing for flexibility as new and unexpected customization options emerged[1]. Data saturation was achieved when no new customization option was identified across three consecutive rounds, with each round consisting of a randomly selected block of six CHIMs [1].

2.1.2. Comparative analysis of customization options

A quantitative content analysis was conducted to systematically examine and compare the identified user-centered customization options, following a three-step process, as shown in Figure 2.

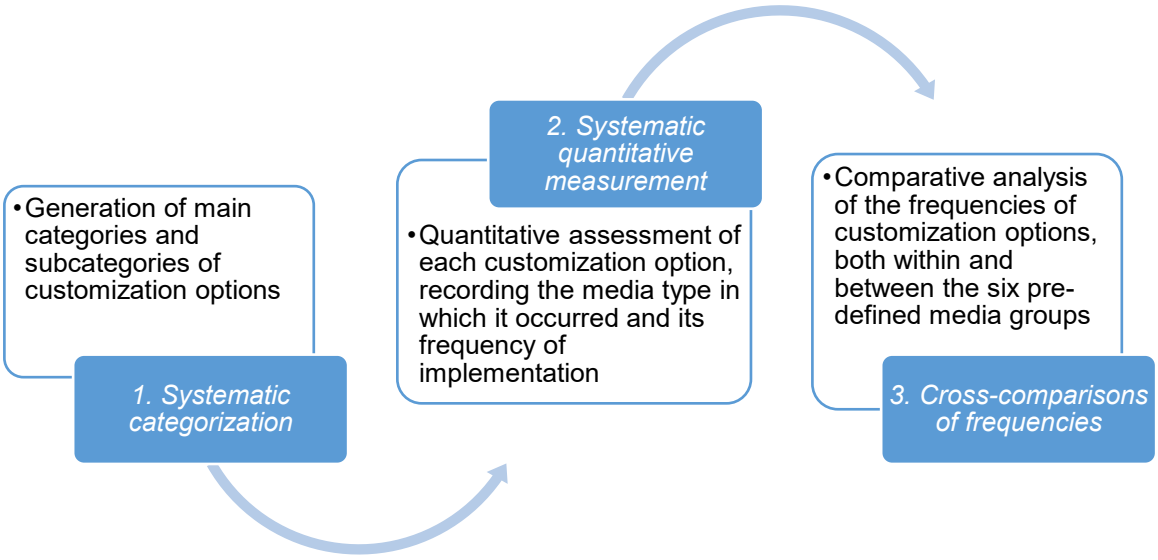


Figure 2: Quantitative content analysis

The quantitative content analysis aimed to determine: (1) the mean number of customization options within each main category across different media types, and (2) the proportion of CHIMs within each media type that offered at least one customization option [1].

A standardized data collection matrix in Microsoft Excel was utilized for data recording and frequency analysis.

2.1.3. Extended analysis of customization options

To complement the initial quantitative content analysis and identify any further potentially relevant customization options that might have been overlooked, an extended exploratory analysis was conducted from July 2023 to September 2023. This step focused on websites, given their flexibility in implementing customization options through specialized programming technologies and their platform-independent accessibility across various devices such as computers, tablets or smartphones. Websites were randomly selected from the pool of CHIMs established in Phase 1 to maintain an unbiased sample.

The extended analysis was conducted iteratively until data saturation was achieved. This was defined as the point at which the analysis of additional websites yielded no new, or only marginally new, relevant customization options. A ‘new’ option was defined as a customization option that belonged to a completely new main category. A ‘marginally new’ option was defined as a customization option that belonged to an existing subcategory. The extended analysis was conducted by the author of the thesis.

The website analysis was conducted in several rounds, following an iterative process:

1. *Analysis phase*: Each round consisted of an analysis of ten websites.
2. *Adaptation of round size:* If the number of new or marginally new options decreased by at least 50% across two consecutive rounds, the subsequent round size was increased from 10 to 15 websites. This adjustment aimed to mitigate the risk of overlooking relevant options due to random fluctuations in the distribution of customization options on websites.
3. *Security round:* If no new or marginally new relevant customization options were identified after the adjusted round, a final security round of five websites was analyzed. The search was terminated if no new relevant customization options were identified in the security round.

2.2. Conceptualization of the toolbox (Phase 2)

2.2.1. Preliminary version of the toolbox

Based on the findings of Phase 1, a preliminary version of the toolbox was developed between October 2023 and February 2024. This initial draft aimed to consolidate all identified user-centered customization options into a clear, structured overview, serving as a foundation for subsequent refinements.

Each customization option was defined with standardized terminology to ensure consistency, accompanied by a description of its purpose and potential benefits for consumers of health information.

In order to demonstrate the practical applicability of the toolbox, preliminary illustrative examples of user-centered customization options have been added, which were drawn from the representative sample and findings from the extended website analysis.

2.2.2. Critical reflection of the toolbox

In March 2024, the preliminary version of the toolbox was presented during a three-hour internal workshop at the Institute of General Practice and Evidence-based Health Services Research at the Medical University of Graz, to discuss its further development and evaluate its relevance and practicability.

The workshop was moderated by the author of this thesis. The workshop was attended by a multidisciplinary team of seven experts with varying degrees of experience and expertise in the field of CHI and health communication. The participants had scientific and practical backgrounds in fields such as evidence-based medicine, health and nursing sciences, public health, health services research, primary health care, health literacy, patient involvement and communication, and health management.

The multidisciplinary perspectives enabled a critical reflection on the toolbox, resulting in a comprehensive evaluation of the customization options' applicability.

Principally, the workshop pursued two central objectives:

1. *Identification of additional user-centered customization options:* Through a brainstorming process, participants of the workshop were encouraged to suggest additional user-centered customization options that had not yet been considered in the toolbox. Participants first brainstormed individually, then shared and discussed their ideas and relevance of newly proposed options in the group.
2. *Gathering feedback on the comprehensibility of the preliminary toolbox version:* The comprehensibility of the preliminary version was evaluated through an open discussion among the participants focusing on the clarity of the categories, precision of descriptions, potential benefits, and practical examples of the user-centered customization options. Participants were encouraged to share their professional perspectives by identifying points of confusion, proposing improvements, and discussing the toolbox's practical applicability.

The results of the workshop were documented in a protocol, serving as a guide for the subsequent refinement of the toolbox.

2.2.3. Expert interviews with publishers of CHI

The second phase of the toolbox development process included a qualitative exploration through interviews with publishers of CHI. The aim of this expert interviews was to analyze their experiences in implementing user-centered customization options, to identify additional relevant customization approaches and to inquire their expectations for the final version of the toolbox.

To ensure methodological rigor and transparency, the reporting of the expert interviews follows the reporting guideline COREQ (consolidated criteria for reporting qualitative research). The completed COREQ checklist can be found in the Appendix 6.

Survey method

Guideline-based, semi-structured individual interviews were conducted with publishers of CHI. This method allows for a systematic but flexible dialogue, whereby an interview guide was created to serve as an orientation guide for the interviewer, ensuring that all relevant topics are addressed during the interview process. All interviews were conducted by the author of the thesis. At the time of the research, the author had no experience in conducting interviews for research purposes. To prepare, the author received practical guidance on interviewing techniques under the close supervision of their main supervisor and a research colleague with extensive experience in qualitative methodologies. In addition, the interviewer had no professional experience in the development of CHI, which positioned the interviewer as an outsider to the field. This minimized the risk of bias arising from established preconceived assumptions.

Interview guide

The interview guide served both a control und structuring function. An interview guide was developed from the author of this thesis in collaboration with the supervisors of the thesis. The questions were formulated in an open-response format. The interview guide followed a consecutive sequence, which could, however, be adapted to the flow of the conversation at any time. However, the interview guide was not guided by a pre-existing theoretical framework.

The final interview guide consisted of three main topics with nine subsidiary questions:

1. The **primary focus** of the interviews was the publishers' experiences with implementing the various user-centered customization options presented, especially the challenges encountered during implementation. This topic was explored using a problem-centered interview approach to capture subjective perceptions, challenges, and, where applicable, possible solutions.
2. The **second focus** was to inquire about any additional known ways to personalize health information for consumers.
3. Finally, the **third focus** in the interviews addressed publishers' expectations for the final toolbox, particularly regarding its level of detail and practicability. The aim of this question was to ensure that the final toolbox would be designed meaningful and usable in practice.

The complete semi-structured interview guide can be found in Appendix 2.

Pre-test of the interview guide

The interview guide was pre-tested with four individuals possessing expertise in qualitative research, health literacy, evidence-based medicine and general practice. These participants were selected to provide diverse perspectives on the guide. The primary objective of the pre-test was to evaluate the methodological quality, comprehensibility and relevance of the questions as well as to assess the appropriate interview duration, the coverage of relevant topics, and the logical flow of the dialogue. In addition, the technical functionality of the audio recording, which was used for all interviews, was tested as part of the pre-test.

Ethical considerations

The ethics committee of the Medical University of Graz approved the conduction of the interviews (see Appendix 3). The interview participants were informed that their participation is entirely voluntary, and that all data collected would be treated in strict confidentiality. It was explicitly stated that the data would be analyzed anonymously. Interview participants had the right to withdraw their consent to data collection at any time without providing a reason. Additionally, they were informed of their right to discontinue the interview at any time without justification. All data were securely stored on a safe server. Finally, for data protection reasons, participants were informed that all audio files and transcripts would be deleted upon completion of the qualitative content analysis. A comprehensive data protection declaration and consent form can be found in Appendix 4.

Recruitment of interview partners

Potential interview partners were recruited through purposive sampling. This approach enables the deliberate selection of individuals who possess specific expertise and experience relevant to the research question, thereby ensuring the collection of practice-relevant insights [112]. For the purposes of this thesis, experts with specialized knowledge and practical experience in the development of CHI were chosen as interview participants.

In order to capture a broad range of perspectives and experiences on the implementation of user-centered customization options in CHI, a heterogeneous sample of interview partners was selected based on following criteria:

1. *Professional experience:* Interview partners were selected to represent varying levels of professional experience levels in the field of health communication, ranging from early-career professionals (<10 years) to highly experienced experts (>10 years). It was hypothesized that those with extensive experience could offer valuable insights into long-term developments and established practices, whereas those with less experience might contribute new perspectives and innovative approaches.
2. *Field of expertise:* Particular emphasis was placed on selecting interview partners with diverse professional backgrounds, as the development of CHI requires expertise in multiple specialized areas, including technical, linguistic, design, communication and management skills.
3. *Number of employees of the publisher's organization:* The number of employees served as another selection criterion to categorize the size of the publishing organizations. Publishers were classified as 'small' (10-49 employees), 'medium' (50-249 employees), or 'large' (250 or more employees). The assumption was that larger publishers, benefiting from greater resources and more established organizational structures, would have more experience in managing complex projects. In contrast, smaller and medium-sized publishers were expected to be more agile and flexible in developing new approaches, although resource constraints might limit the ability to scale up projects.
4. *Geographical scope:* The understanding of health, illness, and health behavior can differ significantly between countries, potentially influencing both the development and perception of CHI. In order to control for these differences, it was intended to recruit interview partners from the primary German-speaking countries: Germany, Austria, and Switzerland. While cultural differences do exist within these regions, they are generally smaller than those observed across broader linguistic and cultural contexts.

Interview process and documentation

Potential interview partners were contacted in advance by the author of the thesis via telephone or email. The initial inquiry informed participants that the interviews are conducted for the purpose of a dissertation project. The potential interview partners were informed that the thesis is embedded within a larger research project aimed at designing and developing an interactive and adaptive consumer health information system (A+CHIS). The inquiry also outlined the specific objectives of the interviews as part of the research project, the estimated interview duration (approximately one hour), and data protection regulations. If participants agreed to take part, they were provided with a consent form, which had to be signed before the interview. Once consent was obtained from a CHI publisher, the interview was scheduled and conducted promptly.

The author of the thesis conducted all interviews either in person or via video conference (Webex). Efforts were made to ensure that both in person and online interviews were conducted under comparable conditions, including a quiet environment and reliable technical equipment. All interviews were recorded using a Philips DVT4000 dictation device, with explicit prior consent obtained as part of the consent declaration. The audio files and transcripts were stored in an encrypted drive, with passwords in place to protect their confidentiality. In the analysis and presentation of the results, no names or other personally identifiable information of the interview partners were disclosed.

Subsequently, all interviews were transcribed verbatim using the transcription software Sonix [113], following the content-related semantic transcription rules outlined by Dresing and Pehl 2018 [114]:

1. Word slurs were brought closer to written German, e.g., “hama” becomes “haben wir”.
2. Dialects have been translated as closely as possible into standard German.
3. Colloquial words have been transcribed.
4. Stuttering was smoothed out or omitted, broken words were ignored. Double words were only recorded if they were used as a stylistic device for emphasis, e.g., “Das finde ich sehr, sehr wichtig.”
5. Receptive signals, such as „hm, aha, ja, genau“, that did not interrupt the other person's flow of speech, were not transcribed. They were transcribed if they were given in direct response to a question.
6. Pauses were not transcribed.
7. The interviewer was referred to as “I” and the interview partner as “IP”.

To prepare the interview partners for the discussion, relevant information about the main topics covered in the interview was provided in advance. Additionally, the presentation slides used during the internal reflection workshop (*2.2.2 Critical reflection of the toolbox*) were shared. However, the full interview guide was deliberately not sent out beforehand to ensure spontaneous and unbiased responses.
At the beginning of each interview, the importance of the research topic, the methodology used to develop the preliminary toolbox, and the preliminary toolbox itself were presented.

Data analysis

The transcripts were analyzed using a content-structuring qualitative content analysis according to Kuckartz and Rädiker 2024 [115]. This approach is characterized by a systematic, rule-based procedure that allows for both deductive and inductive categorization. Figure 3 provides an overview of the procedure for the content-structuring content analysis as outlined to Kuckartz and Rädiker 2024. Given the manageable amount of data to be analyzed, the transcripts were processed using an Excel file, rather than specialized qualitative analysis software. The author of this thesis was responsible for coding the data.

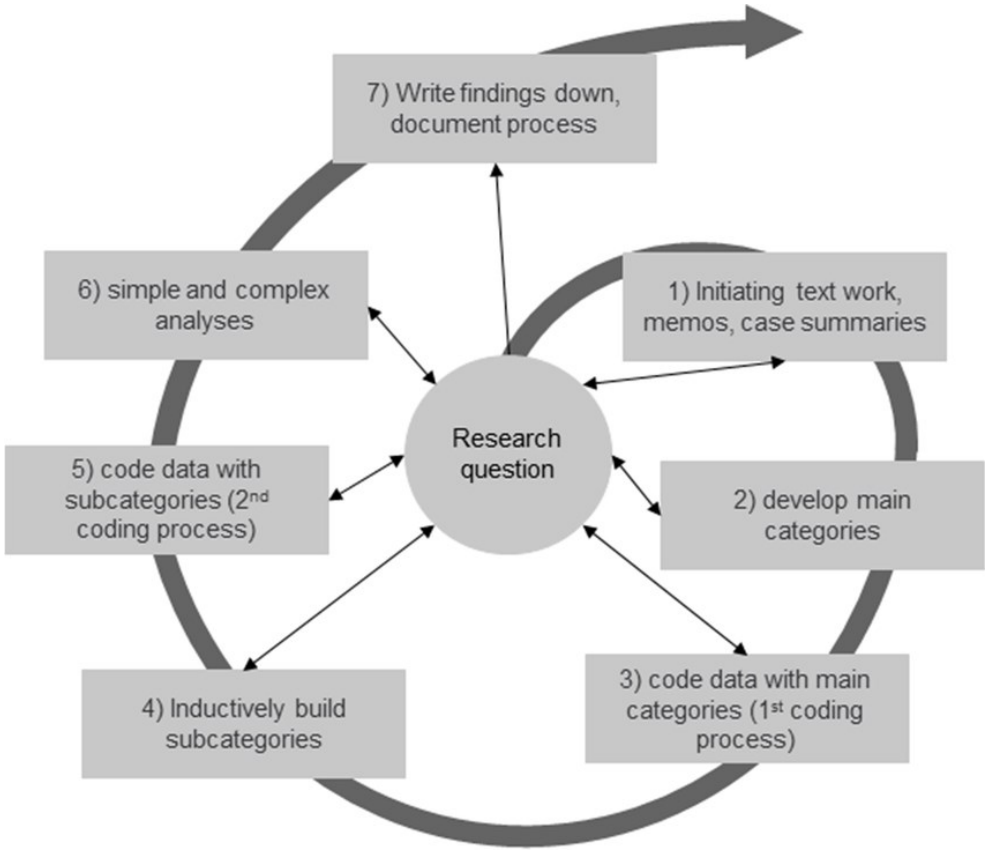


Figure 3: Qualitative structuring content analysis according to Kuckartz and Rädiker 2024 [115]. Translated and reproduced from Müller et al. [116] with permission of publisher BMC Palliative Care. The figure was published in an open-access article distributed under the terms of the Creative Commons CC BY license 4.0 (http://creativecommons.org/licenses/by/4.0/).

First, each transcript was read and reread intensively to familiarize with the data material. Thereby, key quotes were highlighted and any noteworthy issues were documented as memos. Memos are notes taken by the author of the thesis during the analysis process to document ideas and assumptions that arise [115].

The next step entailed the paraphrasing of individual quotes in order to reduce the amount of the data material. Passages that were not relevant to the content or did not contribute to answering the questions were not paraphrased.

Subsequently, the paraphrased quotes were categorized. Thereby, initial main categories were generated deductively based on the main topics pre-defined in the interview guide.
For the first two topics, '*Experiences and challenges with the implementation of user-centered customization options*' and '*Additional personalization methods',* the paraphrased quotes could be coded into predefined subcategories derived from the preliminary toolbox version. No additional inductive category development was necessary for these two topics.
For the third topic, '*Expectations of the final toolbox*', a deductive-inductive approach was applied. The initial deductive phase was followed by an inductive fine-coding phase, where each quote was paraphrased to extract the key statement. The paraphrases were then generalized and systematically categorized into subcategories (Table 3).

Table 3: Example of deductive-inductive categorization - '*Expectations of the final toolbox*'

IP	Main category	Quote	Paraphrase	Generalization	Sub category
IP1	Erwartung an die finale Toolbox	„Ich finde, wenn man das digital gestaltet, wäre es glaube ich erstens einfacher nutzbar und zweitens würde ich es eher nutzen, als dass ich mir ein PDF aufmache und das durchscrolle. Aber das ist vielleicht auch eine persönliche Geschichte."	digitale Version einfacher nutzbar, erhöht die Nutzungs-wahrscheinlichkeit der Toolbox, persönliche Präferenz	Präferenz für digitales Format	Format der Toolbox

2.3. Finalization of the toolbox (Phase 3)

In the final phase of the toolbox development process, formerly all the user-centered customization options identified in phases 1 and 2 were consolidated and categorized into a comprehensive overview.

In addition, the toolbox was refined based on potential annotations from the reflective workshop and expert interviews with publishers of CHI conducted in phase 2.

Furthermore, the illustrative examples, which were created in the preliminary version of the toolbox, were extended and refined. This was based on considerations from the author of the thesis relying on a knowledge that was built up in the course of the research project and a deeper understanding of each customization option. This was subsequently supplemented with targeted online searches aiming to identify explicit easy-to-understand examples.

In addition, the finalization step included the formulating of key considerations in case of implementing customization options (*"Points to consider in case of implementation"*). These considerations based on several information sources: (1) results from the expert interviews with publishers of CHI, (2) results from the targeted online search, and (3) results from a supplemented focused PubMed search for considerations requiring more robust scientific evidence using MeSH-terms and relevant key search terms. The supplementary PubMed searches were designed to be focused and not systematic. They served to quickly identify recent and relevant literature on key considerations for implementation of specific customization options.

3. Results

This chapter presents the results derived from the three-phase development process of the toolbox. Furthermore, the end result of this process – the final toolbox – is also presented in detail within the sub-chapter 3.3. on phase 3 ‘Finalization of the toolbox’. This sub-chapter also provides an overview of the established categories of user-centered customization options and outlines how the final toolbox is structured.

3.1. Exploration of customization options (Phase 1)

3.1.1. Results from the state-of-the-art review

The final pool included 1228 CHIMs about T2DM across different media formats. The representative sample used for the analysis consisted of 114 CHIMs, i.e. data saturation was reached after 19 rounds of randomization, with 19 CHIMs analyzed from each of the six pre-defined media groups. Figure 1 illustrates the random selection process for the representative sample [1].

A total of 24 different user-centered customization options were identified in the representative sample, which were grouped into 5 main categories: (1) language, (2) text, (3) audio-visualization, (4) presentation, and (5) medical content. The majority of these options were found in the categories of language, text, and audio-visualization, with a range of one 1 to 17 in one CHIM. The only medium which did not provide any possibility for customization were p-HI (Table 2). However, almost two-thirds (65%) of the analyzed CHIMs in the representative sample did not offer any possibility to customize the information to individual needs of consumers [1].

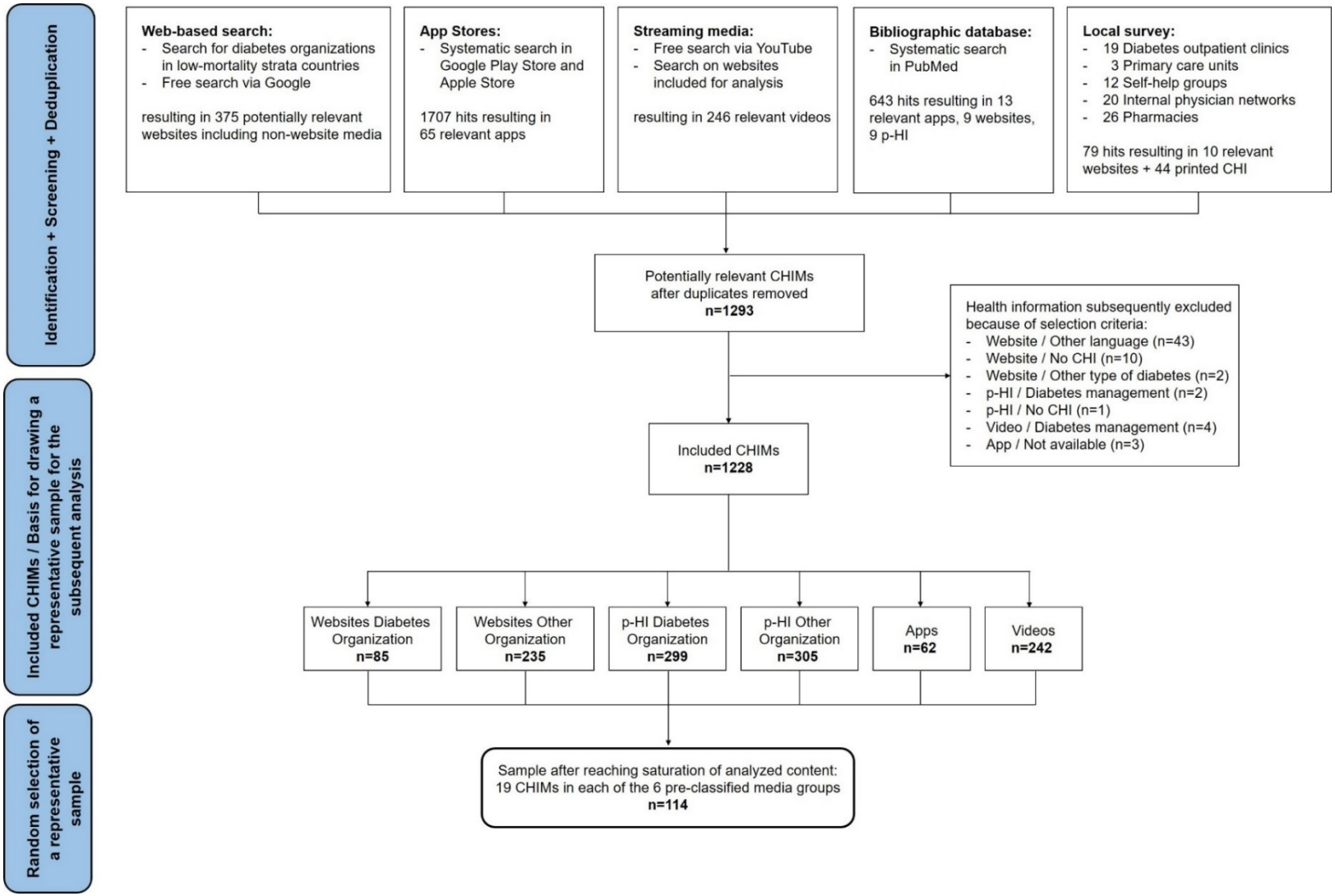


Figure 4: Flowchart of the random selection process for the representative sample of CHIMs. Reproduced from Krenn et al. [1] with permission of publisher Frontiers in Public Health. The figure was published in an open-access article distributed under the terms of the Creative Commons CC BY license 4.0 (http://creativecommons.org/licenses/by/4.0/).

Table 4: User-centered customization options in different types of media. Reproduced from Krenn et al. [1] with permission of publisher Frontiers in Public Health. The figure was published in an open-access article distributed under the terms of the Creative Commons CC BY license 4.0 (http://creativecommons.org/licenses/by/4.0/).

		Types of media of CHI					
		WDO (n=19)	**WOO (n=19)**	**p-HI DO (n=19)**	**p-HI OO (n=19)**	**App (n=19)**	**Video (n=19)[a]**
Main categories of customizations and modifiable features	**Language customization**	**6 (32%)**	**8 (42%)**	**0**	**0**	**4 (21%)**	**15 (79%)[b]**
	Language of content	6 (32%)	8 (42%)	0	0	4 (21%)	0
	Language of subtitles	na	na	na	na	0	15 (79%)[b]
	Text customization	**2 (11%)**	**4 (21%)**	**na**	**na**	**2 (11%)**	**15 (79%)[b]**
	Font and background	2 (11%)	3 (16%)	na	na	1 (5%)	15 (79%)
	Font style	0	2 (11%)	na	na	0	15 (79%)[b]
	Font size	2 (11%)	3 (16%)	na	na	1 (5%)	15 (79%)[b]
	Text spacing	0	2 (11%)	na	na	0	0
	Font color	0	2 (11%)	na	na	1 (5%)	15 (79%)[b]
	Font opacity	0	0	na	na	0	15 (79%)[b]
	Character edge style	0	0	na	na	0	15 (79%)[b]
	Color of the text background	0	2 (11%)	na	na	1 (5%)	15 (79%)[b]
	Opacity of the text background	0	0	na	na	0	15 (79%)[b]
	Screen masking	0	2 (11%)	na	na	0	0
	Color of the text field	0	0	na	na	0	15 (79%)[b]
	Opacity of the text field	0	0	na	na	0	15 (79%)[b]
	Show or hide subtitles	na	na	na	na	0	15 (79%)[b]
	Text to speech	1 (5%)	3 (16%)	na	na	1 (5%)	na
	Read aloud only	1 (5%)	3 (16%)	na	na	1 (5%)	na
	Highlighted read-aloud text	1 (5%)	2 (11%)	na	na	0	na
	Automatic scrolling of reading text	1 (5%)	2 (11%)	na	na	0	na
	Reading speed	1 (5%)	2 (11%)	na	na	0	na
	Reading volume	1 (5%)	2 (11%)	na	na	0	na
	Presentation customization	**0**	**2 (11%)**	**0**	**0**	**0**	**na**
	Different visualizations	0	2 (11%)	0	0	0	na
	Audiovisual customization	**na**	**na**	**na**	**na**	**1 (5%)**	**18 (95%)**
	Playback speed	na	na	na	na	0	18 (95%)
	Audio transcription	na	na	na	na	1 (5%)	15 (79%)
	Medical content customization	**1 (5%)**	**2 (11%)**	**0**	**0**	**0**	**na**
	Level of detail of information	0	1 (5%)	0	0	0	na
	Prioritization of information	1 (5%)	1 (5%)	na	na	0	na
Total customization options across all main categories, n (%[c])		**9 (12%)**	**16 (21%)**	**0**	**0**	**7 (7%)**	**48 (84%)**
Total modifiable features, n (%[d])		**14 (4%)**	**38 (10%)**	**0**	**0**	**9 (2%)**	**198 (65%)**

[a] YouTube videos (n=18), [b] change of subtitle, [c] calculation refers to all possible adaptable categories, [d] calculation refers to all possible modifiable features;
CHI: consumer health information, DO: diabetes organization, na: not applicable, OO: other organization p-HI: printed or printable health information, WDO: website of diabetes organization, WOO: website of other organization

3.1.2. Results from the comparative analysis

User-centered customization options were offered in websites, apps and videos to varying degrees. However, across all types of media in the representative sample, consumers were offered only 15% of all possible customization options. The highest implementation rate was observed for videos (65%), followed by websites (7%). The lowest implementation rate was demonstrated by apps (2%), while p-HI did not provide consumers with any option to customize the health information [1].

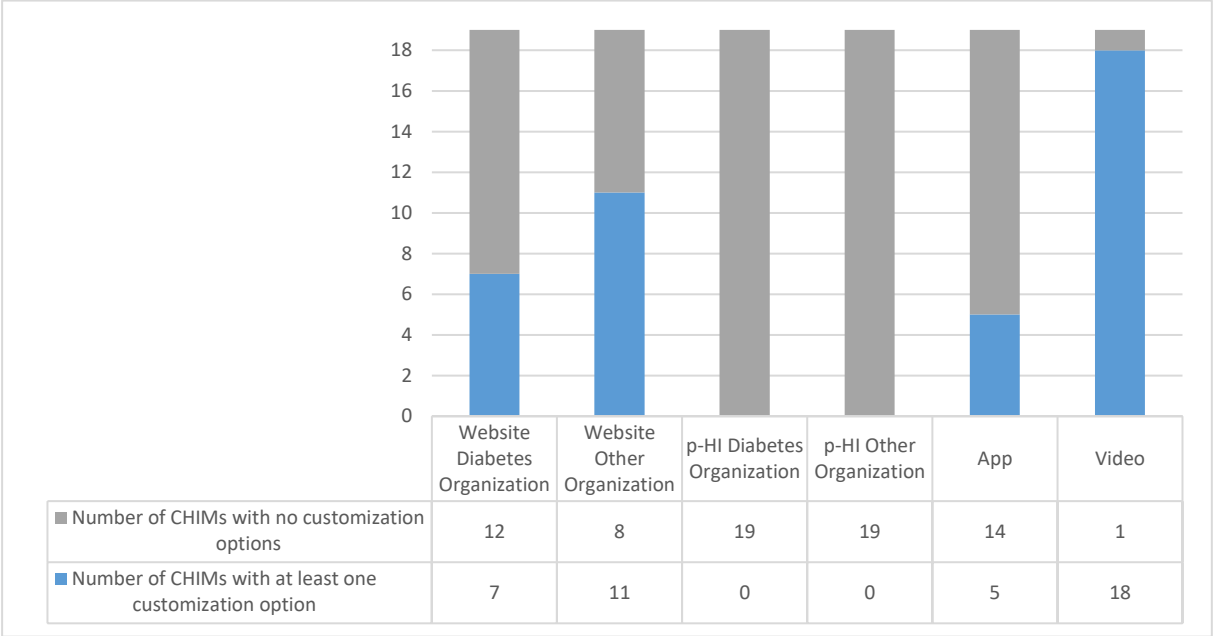
Regarding the videos, the identified customizations were mainly related to the editing of subtitles, for example by changing text elements such as font and background, customizing the language of the subtitle, and controlling audiovisual elements such as playback speed and displaying automatically generated audio transcriptions with timestamps. Almost all of the videos analyzed in the representative sample (18 out of 19; 95%) came from the platform YouTube. On YouTube, subtitles are available by default if they have been added by the publisher of the video or if they have been automatically generated by YouTube. In the representative sample, this was the case for 15 out of 18 (83%) YouTube videos. Additionally, the playback speed could be changed for almost all videos (18 out of 19; 95%). However, the identified customization options in videos did not modify the type of presentation or medical content [1].

Concerning the analyzed websites, overall, consumers had few options to personalize the health information. In the representative sample, WOO (11%-42%) offered more customization options for consumers than WDO (0%-32%). The most customizations were possible in the categories of language (32% (WDO) - 42% (WOO)) and text (11% (WDO) - 21% (WOO)). Overall, only 3 websites (8%) offered the opportunity to customize the medical content, such as choosing the preferred level of detail of information as well as filtering and prioritizing the preferred information based on an algorithmic mechanism using a personal profile generated about the individual's diabetes situation. Furthermore, only 2 websites (11%) allowed consumers to change the way the information is presented, i.e. to display the same information in different visualizations. Data on the prevalence and incidence of diagnosed diabetes were presented statically in the form of running text, bar charts, time series and tables. Furthermore, risk factors for diabetes by age, sex, ethnicity and education were also presented interactively at national, state and county levels. The different visualizations were presented to consumers simultaneously or separately [1].

Among the analyzed apps, only 26% (5 out of 19) allowed consumers to modify the health information to their individual preferences. Available customization options included language selection, adjustments to font size, font color, color of the text background, text-to-speech (read aloud) and audio-transcriptions (see Table 2) [1].

Number of possible customizations across main customization categories in different types of media

The analysis indicated a gap in customization option across the different CHIMs formats. It was found that most CHIMs have not provided the full range of options to consumers that are theoretically possible (Figure 5). Although modifications are theoretically feasible for p-HI, such as multi-language column layouts, this option was not made available to consumers. Furthermore, websites can theoretically be customized in four categories (language, text, presentation, medical content) and apps in all categories. However, the websites and apps included in the representative sample, offered customizations in a maximum of two categories. Regarding the videos examined, a total of 15 (79%) offered customization options across all possible categories [1].



	Website Diabetes Organization	Website Other Organization	p-HI Diabetes Organization	p-HI Other Organization	App	Video
Number of CHIMs with no customization options	12	8	19	19	14	1
Number of CHIMs with at least one customization option	7	11	0	0	5	18

Figure 5: Mean number of customization options in the main categories in which it was theoretically possible. Reproduced from Krenn et al. [1] with permission of publisher Frontiers in Public Health. The figure was published in an open-access article distributed under the terms of the Creative Commons CC BY license 4.0 (http://creativecommons.org/licenses/by/4.0/).

Number of at least one customization option across the different types of media

The number of CHIMs that offered at least one user-centered customization option compared to those that did not varied between the media types (Figure 6). The analysis revealed a discrepancy between the websites of diabetes organizations and those of other organizations with 37% versus 58%, respectively. Almost all of the videos (95%) analyzed offered at least one customization option. In contrast, this was significantly less common in the apps, with only approximately a quarter (26%) enabling some form of modification for consumers [1].

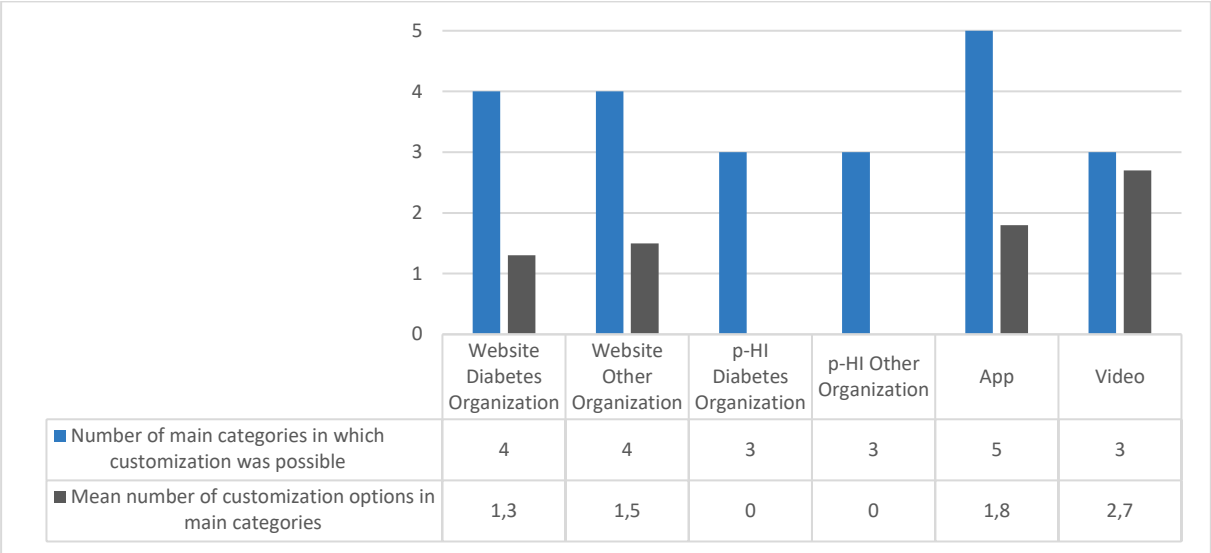


Figure 6: Number of CHIMs without versus at least on customization option in different media types. Reproduced from Krenn et al. [1] with permission of publisher Frontiers in Public Health. The figure was published in an open-access article distributed under the terms of the Creative Commons CC BY license 4.0 (http://creativecommons.org/licenses/by/4.0/).

3.1.3. Results from the extended analysis

The extended website analysis to identify additional user-centered customization options was conducted iteratively across four search rounds, examining a total of 40 websites. Ultimately, three new and three marginally new customization options were identified through this search process (Table 5).

Table 5: Results of extended website analysis for further customization options

Search round	Websites	Customization option	Main category	Sub category
1	10	Plain language (N)	Language	na
		Easy language (N)	Language	na
		Risk calculators (MN)	Presentation	Special visualization
		Converter tools (MN)	Presentation	Special visualization
2	10	Sign language (N)	Language	na
		Educational features (MN)	Presentation	Special visualization
3 (adjusted round)	15	Interactive data visualizations (MN)	Presentation	Special visualization
4 (security round)	5	-	-	-

Abbreviations: na: not applicable; N: new; MN: marginally new

The initial round analyzed ten websites revealing four customization options: two concerning language versions simplifying medical text and two involving specialized visualization types enhancing interactivity and user-friendliness.

In round 2, examining the next 10 websites, two further customization options (sign language and one additional visualization type) could be identified. As the number of new options identified in round 2 decreased by 50%, the sample of analyzing websites for round 3 was increased to 15 websites, as per defined methodology. This round identified only one further specialized visualization type.

As round 3 identified no further relevant new options, a final security check (round 4) was conducted on five websites. The final round confirmed the previous finding, identifying no additional relevant new or marginally new customization option.

3.2. Conceptualization of the toolbox (Phase 2)

3.2.1. Results from the preliminary version of the toolbox

The preliminary version of the toolbox included four main categories of customization options: (1) language, (2) presentation, (3) text, and (4) audio-visualization, encompassing a total of 26 individual user-centered customization options.

A comprehensive overview of all identified customization options during the development process has been provided in tabular format, indicating their possible implementation in either electronic or print media (Appendix 5).

During the development of the toolbox, the Web Content Accessibility Guidelines (WCAG) 2.2[2] (dated 12 December 2024) [117] were identified. The WCAG provide a wide range of recommendations to make web content more accessible for people with various impairments, including blindness and low vision, deafness and hearing loss, limited movement, speech disabilities, photosensitivity, learning disabilities and cognitive impairments. Further information to WCAG can be found in chapter *3.3.3 Web content accessibility customization options*. A key finding of this thesis was that all customization options allocated to the third (text) and fourth (audio-visualization) category in the preliminary toolbox, fall under the scope of the WCAG. Consequently, as established standards already address these areas, they are not the primary focus of this toolbox. Instead, the toolbox primarily details customization options within the first two categories, outlining their objectives, benefits, and providing illustrative examples. However, the WCAG-related tools are included in the toolbox to raise awareness among publishers of CHI and encourage their use alongside the core customization options presented in this toolbox.

[2] The version 3.0 of the WCAG is in progress (working draft; status: 12 December 2024).

3.2.2. Results from the critical reflection of the toolbox

The internal workshop at the Institute of General Practice and Evidence-based Health Services Research at the Medical University of Graz conducted with a multidisciplinary team of seven experts resulted in the identification of six additional individual user-centered customization options, as shown in Table 6. All identified options were incorporated into the final toolbox as illustrative examples.

Table 6: Additional user-centered customization options identified in the internal workshop

Main category	Customization option
Language	Customization of print media by incorporating a QR code that links to audio-visual materials in multiple languages
	Visual language, e.g., pictograms
Presentation	Customization of video type, e.g., animation, expert lecture
	Presentation of risk communication using numbers and visuals
	Filtering of information for drugs with warning signals for specific risks, e.g., highlighting drugs that may cause weight gain in individuals with obesity
	Information basket for storing information requested by consumers

Discussions about the comprehensibility and practicability of the preliminary toolbox led to three main suggestions for improvement:

1. *Illustrative examples*: Four participants recommended including more examples for each customization option to improve the toolbox's practical value for CHI publishers.
2. *Category consolidation*: One participant suggested combining the text and audio-visualization categories into the unified category '*Web content accessibility customizations*, as both categories refer to WCAG [117].
3. *Redundant media distinction*: Two participants suggested removing the distinction between electronic and print media in the tabular overview of customization options (Appendix 5). They considered that this distinction is superfluous, as the media format in which implementation is possible is self-explanatory. Instead, they recommended adding information about the target group for each customization option.

3.2.3. Results from the expert interviews with publishers of CHI

For this study, six interviews were conducted with publishers of CHI form different organizations. Five of these interviews were conducted as individual discussions, while one interview was conducted jointly with two experts. In total, seven experts were interviewed. The interviews were conducted over a period of three weeks in April and May 2024. Each expert was interviewed once. No interview was repeated. The author of this thesis had a pre-existing professional relationship with two of the seven interview partners (joint interview). The remaining five experts were unknown to the author prior to recruitment for the study.

After completion of the interview phase, one experts' organization was dissolved due to political reasons. Nevertheless, this had no influence on the data collection process that had already been completed.

While the initial recruitment plan aimed to include publishers from the three main German-speaking countries (Germany, Austria, and Switzerland), recruitment efforts in Switzerland unfortunately remained unsuccessful. Inquiries directed to three Swiss organizations did not result in interview participant engagement. According to a health literacy expert from Switzerland, the development of health information materials in Switzerland predominantly involving health insurance companies, individual journals, or sometimes the Federal Office of Public Health, making them not directly comparable to those in Germany and Austria.

From the six interviews conducted, one was conducted in person at the interview partners place of work and the other five were conducted via video conference. The interviews lasted on average one hour. All interview participants accepted the invitation to participate immediately, due to the high level of interest in the topic of health communication. Furthermore, all interviews were conducted in a quiet setting with only the researcher and the individual interview partners present. This was done to ensure confidentiality and to encourage open and honest responses. The transcripts were not returned to the interview partners for comment or correction.

Of the seven interview partners, three had less than 10 years of professional experience, while four had more than 10 years of experience. The interview partners were drawn from a range of organizational sizes, with four from small, one from medium, and two from large organizations (Table 7). The interview partners have various academic educational backgrounds, ranging from health management, communication and political science, science

communication, psychology, biology, and journalism in medicine and science. Their professional expertise in the field of health literacy and health communication encompasses the strategy development and planning of measures to strengthen health literacy, the development of evidence-based CHI and patient guidelines, the preparation of medical content in plain and easy language, the conception and quality assurance of multimedia CHIMs as well as the acquisition of editorial management tasks.

Table 7: Characteristics of interview partners

Interview partner (IP)	Sex	Professional experience (years)	Number of employees of publisher's organization [b]
IP1	Female	<10 years	medium
IP2 [a]	Male	<10 years	small
	Female	<10 years	
IP3	Male	>10 years	small
IP4	Male	>10 years	large
IP5	Male	>10 years	large
IP6	Female	>10 years	small

[a] Interview 2 was conducted with two experts simultaneously.

[b] Number of employees: small (10-49), medium (50-249), large (>250).

3.2.3.1. Experiences and challenges with user-centered customization options

In general, all six interviewed publishers reported that the implementation of user-centered customization options is an extremely resource-intensive process. They emphasized that each customization option requires additional personnel and technical resources, making careful and strategic resource planning essential. However, this challenge was described as more pronounced for small and medium-sized publishers than for larger ones. Consequently, resource constraints often lead small and medium-sized publishers to focus on specific target groups, as implementing a full range of customization options is unfeasible.

Larger publishers particularly emphasized that substantial resources must be invested in the initial development of evidence-based health information for a comprehensive disease catalog, as well as in the necessary regular updates associated with it. Furthermore, additional resources and surveys are essential to address the constantly changing user needs (e.g., the changing user behavior, with an increasing number of people using social media as a primary source for health-related information). Additionally, publishers with a legal mandate often face regulatory obligations that oblige them to implement a broader set of customizations. For

instance, accessibility regulations require them to provide basic information in easy language and sign language, ensuring that content is accessible to people with disabilities.

Chapter 3.3 (Finalization of the toolbox (Phase 3)) includes separate sections outlining experiences and challenges associated with each customization option in detail.

3.2.3.2. Additional user-centered customization options

The interview participants reported several additional approaches to customize CHI. These encompassed two new language customization options (Table 8), as well as seven customizations within the category presentation customization options (Table 9). All additional proposed customization options were included as illustrative examples in the final toolbox.

Table 8: Additional language customization options proposed by publishers of CHI

Customization option	Example
Target-group specific language	Customization the textual content's language to a specific target group, such as students or elderly, while considering the text complexity. For example, CHIMs for students might employ a more academic and technically precise style, whereas for older adults, the text could be formulated using simpler language and a more accessible style, potentially incorporating larger font sizes or supplementary explanations.
Visual language	Customization of text into formats such as comics, emoticons, or pictograms making health information more engaging and accessible. For example, using simple visuals to represent healthy and unhealthy foods to prevent diabetes or obesity. This approach could help make complex health messages easier to understand, especially for audiences who struggle with complex information.

Table 9: Additional presentation customization options proposed by publishers of CHI

Customization option	Example
Different visualizations for same information	***Audio and video formats*:** Presentation of same information as short videos (e.g., reels) or podcasts.
Special visualizations	***Video glossary*:** A collection of videos featuring medical experts who explain and define complex medical terms and concepts.
	***Self-assessment questionnaires*:** Tools that enable individuals to evaluate their physical and mental health status by answering targeted questions. These questionnaires help identify symptoms, assess risk factors, and monitor overall health. Such questionnaires can be used, for example, for the early disease detection, pain intensity assessment, or evaluating lifestyle factors such as diet and exercise.
	***Value clarification tools*:** Instruments designed to help individuals identify, visualize, and reflect on their personal values and preferences. As a key component of decision aids, they support informed decision-making by making individual priorities and beliefs more transparent [118].
Filtering and prioritizing of information	***Filtering of evidence*:** A method for categorizing health information based on the strength of evidence. This approach distinguishes between high-quality, evidence-based CHI and existing research gaps, providing users with a clear overview of the current state of scientific knowledge.
	***Ranking of personal questions*:** A structured process that helps individuals prioritize their own questions when preparing for a consultation with healthcare professionals. By systematically ranking questions based on their importance, users can ensure that the most critical topics are addressed first. This approach also encourages reflection on personal priorities and helps reduce uncertainty regarding specific issues.
	***Pre-filtering of levels of knowledge*:** The simplification of complex information by reducing it into up to four key messages. This method provides consumers with a quick and accessible overview of a topic.

Abbreviations: DiGAS = Digitale Gesundheitsanwendungen

3.2.3.3. Expectations of the final toolbox

The interviewed experts highlighted a diverse range of expectations and requirements regarding the final toolbox, pertaining to both content and design.

Content of the toolbox

A key concern expressed by the publishers was the integration of target-group specific information. Specifically, they requested that the toolbox should provide a comprehensive explanation of which customization options are suitable for which target groups. Furthermore, it was emphasized that the toolbox should reflect the experiences with the customization options of the target groups. It was also suggested that the toolbox should include guidance on which customization options are appropriate for different media channels and which channels are preferred by each target group.

Moreover, the publishers expressed a need for more detailed information on the various customization options. They emphasized that the toolbox should not only list these options but also include several specific examples, outlining their areas of application, advantages and disadvantages, as well as the scientific evidence supporting their effectiveness. A simple listing of customization options was considered insufficient, and purely theoretical information from textbooks or papers was deemed of little practical relevance.

Furthermore, some publishers specifically requested practical implementation instructions, including details on the effort and resources required to implement the customization options. They also considered it valuable for the toolbox to provide concrete assistance, expert contacts, and information on available training workshops.

Design of the toolbox

The publishers highlighted the importance of making the toolbox available in a digital format to ensure flexible and user-friendly access. To enhance its usability, they highlighted that the toolbox should be meticulously structured and equipped with filter functions. Notably, two publishers suggested adding a filter function that would recommend suitable customizations for different target groups and media types, as well as allow filtering based on the scientific evidence supporting these customizations. Another publisher proposed integrating a checklist to support the practical implementation of customization options. Additionally, one publisher expressed a preference for the toolbox to be written in German, aiming to enhance comprehension and ease of implementation for German-speaking publishers.

3.3. Finalization of the toolbox (Phase 3)

In the finalization step of the toolbox, some refinements were made based on recommendations from the internal reflection workshop. First, the differentiation between electronic and print media, which had been designed in the preliminary version of the toolbox (Appendix 5), was removed. Second, the third (text customization) and fourth (audio-visualization customizations) categories were combined into the single and broader category '*Web content accessibility customizations'*, referring to components including in the WCAG 2.2. [117].

Therefore, the final version of the toolbox PHOCUS comprises three main categories of user-centered customization options, with a total of twelve different customization options, as illustrated in Figure 7.

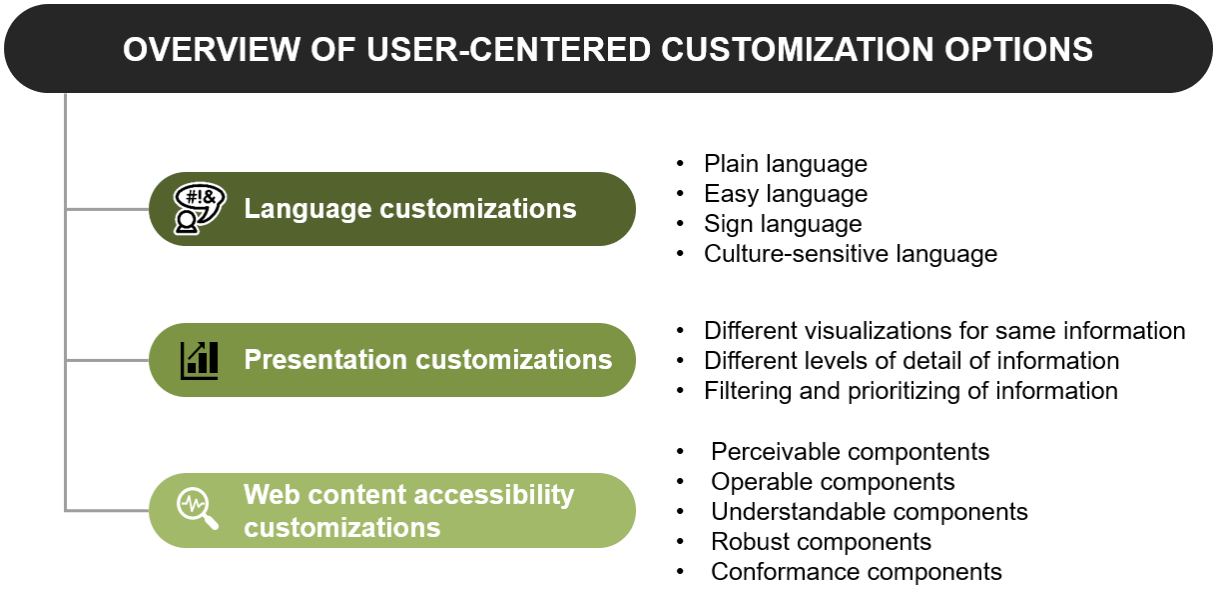


Figure 7: Overview of user-centered customization options in CHI

The supplemented focused PubMed searches aimed to identify publications related to the effectiveness of machine translation tools for creating CHI in plain, easy and sign language, as well as multilingual formats. Following MeSH terms were used: *Artificial Intelligence, Large Language Model, Sign Language* and *Translations*. For plain and easy language, relevant free-text terms were applied, as no corresponding MeSH terms currently exist in PubMed.

It was not feasible to incorporate all the expectations expressed by the experts regarding the design and content of the final toolbox, as this was beyond the scope of this dissertation project. However, it should be noted that the toolbox PHOCUS is conceived as a dynamic tool, intended for continuous expansion, refinements and updates to incorporate new customization options, changing user needs and new scientific evidence.

The final version of the toolbox PHOCUS focuses on the category of language customization options, enabling an in-depth and targeted exploration, and ensuring the dissertation project remains within its defined thematic scope.

Furthermore, PHOCUS was designed as a systematically organized resource providing practical recommendations for implementing user-centered customization options, supplemented with illustrative examples to demonstrate their practical application.

Therefore, the final toolbox for language customization options addresses the following sections:

1. **Definition of user-centered customization option:**
   Descriptions of each customization option's purpose, relevance, and potential benefits.
2. **Target group:**
   Brief indication of intended user groups for each customization option.
3. **Examples:**
   Various practical examples enhancing understanding and practical applicability.
4. **Experiences of publishers of CHI:**
   Reports from publishers facing implementation challenges and possible solutions.
5. **Points to consider in case of implementation:**
   Practical recommendations guiding effective implementation and addressing potential pitfalls.

The second and third categories (presentation customization options and web content accessibility customization options, respectively) are not explored in detail. However, these options are planned to be explored in detail in future research.

While the state-of-the-art review examined CHIMs related to T2DM, the toolbox is designed to be applicable to a wide range of health topics.

3.3.1. Language customization options

The category language includes the customization options (1) Plain language, (2) Easy language, (3) Sign language, and (4) Culture-sensitive language.

3.3.1.1. Plain Language

3.3.1.1.1. Definition

Plain language (in German "*Einfache Sprache*") is oriented towards the B1-language level, as defined by the Common European Framework of Reference for Languages (CEFR) [119-121]. The CEFR-level B1 represents the third level of a total of six levels at the CEFR global scale and is assigned to the category of 'Independent use of language'. Those at the CEFR-level B1 are considered to be at an intermediate stage of proficiency in spoken language. Individuals at CEFR-level B1 are able to understand main points if a clear standard language is used. At this level, individuals are able to engage in spontaneous conversation on topics that are familiar, of personal interest, or pertinent to everyday life, such as family, work, school, leisure, or current events. They are also able to deal with most situations encountered when travelling in an area where the language is spoken. Additionally, they can talk about experiences and events, their dreams and hopes, and give reasons and explanations for opinions and plans. This language level corresponds to everyday speech and is a simplified version of the standard language [119, 120, 122]. Synonyms for plain language are plain writing, layman terms and layperson terms [123].

To date, plain language lacks a single, standard, internationally accepted definition [124], but there is broad international consensus on the principles and core elements of plain language. The main principle of texts in plain language is that they are read fluently. The content and structure of texts are clearly structured. Plain language avoids long, complex sentences and too many foreign words or technical terms. Instead, sentences should be brief, paragraphs and sections concise, and positive words should be employed. Furthermore, the subject, verb and object should be kept close together [121, 122].

The International Plain Language Federation (IPLF) is one of the most important international organizations in the field of plain language, defining plain language as "*a communication if its wording, structure, and design are so clear that the intended audience can easily find what they need, understand what they find, and use that information*." [125]

3.3.1.1.2. Target group

The main target group of CHI in plain language is the general public. In particular, CHI in plain language are intended for people with basic literacy skills, but who have different reading levels, processing speeds or levels of expertise, and who have difficulties in understanding complex and medical terminology. Plain language is not primarily intended for people with communication disabilities, as this language version is characterized by a higher level of comprehension and may be insufficient for individuals with increased communication needs [126, 127].

3.3.1.1.3. Examples

Comparison of standard language and plain language

Table 10 compares medical recommendations written in standard language with their simplifications in plain language.

Table 10: Comparison between standard language and plain language

Standard language	Plain language
"The Dietary Guidelines for Americans recommends a half hour or more of moderate physical activity on most days, preferably every day. The activity can include brisk walking, calisthenics, home care, gardening, moderate sports exercise, and dancing." [128]	"Do at least 30 minutes of exercise, like brisk walking, most days of the week." [128]
"The patient is advised to adhere strictly to the prescribed regimen of medication, which involves taking two tablets of 500 mg each of the antibiotic every eight hours, with the consumption of food to mitigate potential gastrointestinal side effects. Non-compliance with this schedule could result in diminished therapeutic efficacy and possible exacerbation of the condition." [129]	"Take two 500 mg tablets of the antibiotic every 8 hours. It's best to take them with food to avoid stomach problems. Follow this schedule closely to make sure the medicine works properly and helps you get better." [129]
Prior to surgery patients are required to cleanse with this fluid [130].	The day of your surgery, wash your body with this liquid soap [130].
§ 3 Mund-Nasen-Bedeckung (1) Bei der Nutzung von Verkehrsmitteln des Öffentlichen Personenverkehrs und den hierzu gehörenden Einrichtungen und bei dem Besuch einer Verkaufsstätte in geschlossenen Räumen ist eine Mund-Nasen-Bedeckung zu tragen [131].	**Das Tragen von Masken** Alle Menschen müssen im Nahverkehr, Einzelhandel und ähnlichen Einrichtungen geeignete Masken tragen [132].

Choice of words

CHI should use respectful and inclusive words, as language can convey both conscious and unconscious prejudices. Negative or stigmatizing terms can disadvantageously affect the emotional well-being, the motivation of self-management as well as the access to care and disease management. Examples of terms in plain language suitable for CHI (especially in relation to diabetes) are shown in Table 11 [133, 134].

Table 11: Examples of plain language terms for diabetes information [133, 134]

Avoiding words	**Preferring words**
diabetic, patient, consumer, sufferer	Person Person with diabetes Person living with diabetes
normal, non-diabetic, healthy (person)	Person without diabetes
carers	family, friends
disease	condition
mild diabetes	diabetes
mild hypoglycaemia	self-treated hypoglycaemia
control (referring to diabetes, HbA1c or glucose level)	manage glucose levels within/outside target range high/low glucose levels target glucose levels
fail, failing to, failed, failure, e.g. ‘they failed on metformin’	did not, has not, does not
test, testing (glucose)	check(ing), monitor(ing) glucose
treating diabetes, treating patients	managing diabetes

3.3.1.1.4. Experiences of publishers of CHI

Four of the six interviewed publishers of CHI indicated that plain language is used as the standard language for health information. This was justified by the fact that the health information of the publisher's targets individuals with low health literacy, and plain language represents the most common form of communication for this audience. This assumption was partially confirmed in pilot projects and through positive feedback from website users. Another publisher informed that the majority of the texts are written in B1 and B2 language levels. However, another publisher was unable to report any experience of health information in plain language.

One publisher highlighted that the challenge in formulating texts of health information in plain language is to find a balance between the scientific accuracy of the medical content and the comprehensibility of the text for the general public. However, with increasing experience, standard formulations are developed that meet these requirements. Nevertheless, some formulations remain challenging and ultimately require pragmatic decisions.

> *„Die größte Herausforderung die wir eigentlich immer haben ist, wie formuliert man Sachen einfach, ohne dass sie falsch werden. […] Und für manche Probleme gibt es keine perfekte Lösung. Da muss man sich letztendlich entscheiden, ob man möchte, dass der Nutzer das versteht oder das der Inhalt korrekt dargestellt ist." (IP2)*

Moreover, one of the publishers informed that a standard norm for plain language is currently being developed at the national level. This DIN standard is intended to define the principles and characteristics of plain language. With regard to the development of this standard, the publisher expressed the following concerns:

> *„Da kriegt man erstmal irgendwie einen leichten Schrecken, wenn man hört, dass Einfache Sprache so wie Papier genormt werden soll." (IP5)*

3.3.1.1.5. Points to consider in case of implementation

Legal context of plain language

The guideline of evidence-based health information recommends that plain language should be used as the standard language version for CHI [110].

To facilitate the implementation of plain language in German, clear rules were released by the German Institute for Standardization in April 2024. The institute has translated the ISO 24495-1:2023 into German and published two DIN standards:

- *DIN ISO 24495-1:2024-03, Einfache Sprache – Teil 1: Grundsätze und Leitlinien:*
  This DIN provides a clear understanding of what plain language is and how it can be achieved. Its aim is to help authors write comprehensible texts for a broad readership (130).
- *DIN 8581-1:2024-05, Einfache Sprache – Anwendung für das Deutsche – Teil 1: Sprachspezifische Festlegungen:*
  This DIN specifies the general recommendations of ISO 24495-1 particularly for the German language, partly raised to the level of requirements and supplemented by other relevant specifications [135, 136].

The DIN ISO 24495-1 defines four key principles for plain language [137]:

Principle 1: Readers get what they need (relevant)
Principle 2: Readers can easily find what they need (findable)
Principle 3: Readers can easily understand what they find (understandable)
Principle 4: Readers can easily use the information (usable)

These principles based on the concept that a document will be usable if the information is relevant, finable, and understandable.

In particular, the DINs include a comprehensive set of rules pertaining to the composition of German texts in plain language, addressing the following [138]:

- Text level - content, style, and text structure
- Sentence level - sentence length, sentence structure, and tenses
- Word level - word length, and familiarity
- Design level - typographical emphasis, and hyphenation

Consideration of target group

According to one interviewed publisher, it is recommended that publisher should know their target group precisely and take their age, level of knowledge, life situation and other characteristics into account when developing CHI. For example, if the target group are postgraduate students or small entrepreneurs, the text should not be written at the level typically associated with an 8th-grade class. When CHI is targeted at young people, a more modern and youth-friendly language can be used [122, 139]. However, further research is needed to investigate the effect of target-group specific language styles in CHI.

Risk communication in plain language

An evidence-based risk communication should enable realistic estimates about health risk as well as about potential benefits and harms of preventive, diagnostic, therapeutic and rehabilitative measures. A trustworthy risk communication must also inform about knowledge gaps and uncertainty of scientific evidence. The aim of evidence-based risk communication is to ensure that health risks are understood, and benefits and harms of treatments are correctly assessed, and finally, to enable informed-decisions. The effect of evidence-based risk communication depends on how statistical data are communicated. This requires the selection of relevant and reliable numbers as well as an appropriate presentation of effects and potential adverse effects of interventions. Numbers and risks can be presented in a variety of formats, including natural frequencies, percentages, absolute risk reduction, relative risk reduction, and number needed to treat / number needed to screen / number needed to harm (45, 105). However, the perception and interpretation of health risks varies significantly between laypersons and health professionals [140]. Therefore, the guideline of evidence-based health information established recommendations about the presentation of numerical data to laypersons (Table 12).

Table 12: Risk communication in plain language [110]

Strength of recommendation	Recommendation	Quality of evidence
⇓⇓	The risks, benefits and harms should not be presented only verbally.	middle
⇑⇑	Benefits and harms should be presented with absolute rather than relative frequencies.	middle
⇔	The presentation in percent can be used instead of the presentation in natural frequencies for probabilities >1%.	high
⇓?	The use of number needed to treat (NNT), number needed to screen (NNS) and number needed to harm (NNH) is conditionally not recommended.	middle
⇑?	It is conditionally recommended that standardized reference values (e.g., "1 out of 100") be used to present frequencies and that this reference value remain consistent.	high
⇔	Numerical data can be supplemented with graphical illustrations.	low

Legend: ⇑⇑ strong recommendation for an intervention; ⇑ weak recommendation for an intervention; ⇔ medium recommendation; ⇓ weak recommendation against an intervention; ⇓⇓ strong recommendation against an intervention

Machine translation tools

The development of artificial intelligence (AI) systems has accelerated significantly in recent years, driven by the market release of large language models (LLMs) since 2019. LLMs, such as ChatGPT, are characterized by their capacity to analyze complex texts, recognize patterns within them, and generate texts that are both grammatically correct and stylistically appropriate. A key advantage of LLMs is that they are trained on large datasets, enabling them to learn and adapt continuously to new requirements or developments. LLMs can be used for a diverse range of tasks, including text creation, analysis, optimization, summarization, translation, pattern recognition within text, processing audio-visual material, and general information retrieval [141]. However, it is imperative that the texts are accurate in content and linguistically precise to avoid misunderstandings and misinformation [142-144].

Several studies have examined the quality of machine translation tools for translating standard medical texts into plain language. A recent randomized controlled trial investigated the effectiveness of an online automated tool that supports the simplification of written health information, in comparison to usual processes for revising medical texts into plain language.

The online tool showed significantly improved grade reading level, reduced text complexity, decreased use of passive voice and improved word choice and style (common everyday language, minimal and defined medical terms, and active voice) ($p < 0,01$). Results for content, specifically the presence of a clear purpose and the absence of distracting content, did not show a significant difference between the intervention and control group [145].

Another study evaluated the quality of translation of standard medical texts in German into plain German. The study compared source texts with machine-translated texts and human translations in terms of correctness, readability and syntactic complexity. The system used for machine translation was SUMM AI. The study revealed that machine translations had the highest level of comprehensibility in comparison to both human translations and the source texts. However, machine translations contained a higher number of complex syntactic relations than human translations. Additionally, machine translations are more complex than the source texts and contain various types of errors, such as mistranslations of grammatical structures, ambiguous words or numbers, omissions of relevant prefixes or negation, and incorrect explanations of technical terms. In terms of syntactic complexity, human translations produced the most simplified versions (see Table 13) [146].

Table 13: Machine and human translations into Plain German [146]

Source of text	Translation
Source text	Wer bei sich Probleme im Umgang mit Alkohol feststellt, sollte daher unbedingt das Gespräch mit dem Arzt suchen. [...]
Machine translation	Wenn man merkt, dass man mit Alkohol Probleme hat, sollte man unbedingt zum Arzt gehen. [...]
Human translation	Sie glauben: Ich bin vielleicht alkoholsüchtig? Dann sprechen Sie mit Ihrem Arzt.

The authors of the study concluded, that the machine translation tool can be useful for translating correct and syntactically complex texts, but it does not achieve the same quality as human translations. Consequently, human translators remain indispensable for translating health information into plain language, especially into plain German [146].

Furthermore, machine translation tools require a wide range of training data to understand the use and meaning of complex medical terms. Such terms need to be explained in the training data by replacing medical terms with common lay terms, so that the machine learns to communicate them in a simple way (see Table 14) [147, 148].

Table 14: Medical terms and alternative common lay terms [149]

Medical term	Replacing lay term
anaphylaxis	shock, a sudden and severe allergic reaction, stop breathing, poisoning
cerebrovascular disease	stroke
electrolytes	blood salts, a type of necessary salt found in blood
encephalitis	swelling of the brain

Machine translation tools need to learn when an explanation or simplification is needed for terms and which terms can be left unchanged. If the sentence ends with a term that is not known in the training data, the machine translation may stop generating the translation, resulting in incomplete sentences [147].

Moreover, in order to improve the translation quality of medical texts into plain language using machine translation, it is important to use comprehensive and specific prompts. As shown in Lyu et al. (2023), where radiology reports were translated into plain language using ChatGPT and GPT-4: The quality of translation improved from 55.2% to 77.2% using ChatGPT and from 73.6% to 96.8% using GPT-4 after the prompt was optimized to be much clearer. Furthermore, the optimized prompt also reduced the rates of missing, inaccurate and incorrect translations for both ChatGPT and GPT-4. The original prompt provided to ChatGPT merely encompassed a general directive to translate a radiology report into plain language, with no specific instructions concerning the retention of crucial information. The optimized prompt was much clearer [148]:

Please help translate a radiology report into plain language in the following format:

- *First paragraph introduces screening description including reason for screening, screening time, protocol, patient background, and comparison date;*
- *Second paragraph talks about specific findings: how many nodules detected, each lung nodule's precise position and size, findings on lungs, heart, pleura, coronary artery calcification, mediastinum/hilum/axilla, and other findings. Please don't leave out any information about findings;*
- *Third paragraph talks about conclusions, including overall lung-rads category, management recommendation and follow-up date, based on lesion;*
- *If there are incidental findings, please introduce in the fourth paragraph.*

Labeling of CHI in plain language

It is not universally recommended to label CHI as written in plain language, as this may lead to acceptance problems or even stigmatization among the target group [150]. CHI in plain language are intended for a wide audience and should be easy to understand at first time reading. However, explicit labelling as 'plain' may give the impression that the information is only intended for certain groups, which may be rejected by some readers [151].

Review of CHI in plain language

It is recommended that CHI in plain language should be checked by a review group of members of the target group in terms of linguistic clarity, comprehensibility of numbers, risks and probabilities, appropriate selection of images and other visualizations as well as the overall scope and relevance of information. However, the manual review of each CHI by a review group is often not feasible for publishers. One potential solution would be the development of terminology databases that can be reused in other CHI, with these databases being checked once by a review group. Furthermore, it is recommended that the review group receive an appropriate allowance for their review work [151].

3.3.1.2. Easy language

3.3.1.2.1. Definition

Easy language (in German "*Leichte Sprache*") is located at the CEFR-A1 and A2 language levels, as defined by the Common European Framework of Reference for Languages (CEFR) [119, 120, 152]. The CEFR-levels A1 and A2 represent the first two levels at the CEFR global scale. Individuals at CEFR-A1 level are assigned at the beginner language level and are able to understand familiar names, words and very simple sentences. They can communicate in a simple way if the other person speaks slowly and clearly and is willing to help formulate what the person is trying to say. Individuals can introduce themselves and can ask and answer simple questions in case of immediate need or on very familiar topics. Further, they can write short and simple postcards and can fil in forms with personal details. Individuals at CEFR-A2 level are assigned to the pre-intermediate language level and are able to understand sentences and frequently used expressions related to areas of most immediate relevance, such as personal and family information, work, shopping or local area. They can communicate in simple and routine situations involving a simple and direct exchange of information about familiar and routine matters. Moreover, they can read and write (very) short and simple texts messages related to immediate needs [119, 120].

Easy language represents a very simplified form of the everyday language, characterized by a clear and relatively rigid set of rules. The objective of easy language is to convey the most important concrete information in simple, concise and clear sentences [126].

Synonyms for easy language are easy read, easy write, easy info, easy access, easy-to-read and aphasia friendly [123].

Differences between plain and easy language

The two language concepts of plain and easy language are often confused by the broad public and often used synonymously, but they refer to different concepts in the field of linguistic accessibility. Both concepts aim to make texts easier to understand, but they differ especially in terms of the target group, rules, degree of linguistic simplification, type of presentation and review process. In contrast to plain language, easy language modifies the content and structure of the text to a greater extent. The capacity for expression is limited and comprehensibility of the content takes priority over correctness [126].

The main differences between plain and easy language are shown in Table 15. One fundamental difference is the need to accompany every statement in easy language texts with illustrations. Images are an invaluable resource for texts in easy language, providing support

and clarification. Nevertheless, the primary purpose of images in easy language texts is to signalize that the text is in easy language. Another key difference is that texts in easy language have to be reviewed by the primary target group. This ensures that the texts meet the specific needs of the target group and are adapted to their reading skills. Based on the requirements of the target group, sample test solutions and text modules can be developed and dictionary entries for relevant technical terms can be created [126, 153].

Table 15: Main differences between plain and easy language [123, 127]

Plain language	Easy language
Occurrence of subordinate sentences also possible	Short sentences without subordinate sentences
Everyday words, including difficult words	Well-known words, difficult words are explained
Minimum of font size of 12 pt	Minimum of font size of 14 pt (lager text size)
Adequate white space	Lots of white space
Use of images is not obligatory	Use of images to support each statement
No obligatory evaluation of texts	Evaluation of texts through target group

The critique of easy language is that the content is often too simplified and abbreviated, thereby leading to loss of relevant information. Furthermore, the tendency to simplify language can result in a reduced form of expression that is perceived as having low prestige, thus potentially leading to the stigmatization of consumers of easy language. This may result in long term in exclusion rather than inclusion. Another critique is that easy language frequently uses incorrect spelling and grammar [126].

3.3.1.2.2. Target group

The main target group of CHI in easy language are people with cognitive impairments, such as people with dementia, aphasia, autism and psychological disorders of different kinds as well as people with communication impairments and difficulties, whether they have disabilities or not, such as dyslexia, prelingual hearing impairment and functional illiteracy. Functional illiterate people are people with insufficient reading and writing skills despite regular school education. Moreover, easy language has also expanded up to people with limited language skills, such as language learners. However, it is not recommended to use easy language for language acquisition, because it lacks the essential features that are an important part of the regular curriculum [126].

3.3.1.2.3. Examples

CHI in easy language

An example of a CHI on diabetes mellitus in easy language is shown in Figure 8.

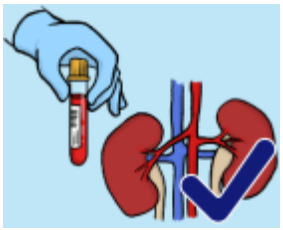
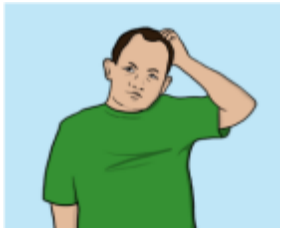
<table>
<tr><th colspan="2">Why are diabetes check-ups important?</th></tr>
<tr><td>  </td><td>Check-ups are important because:
they can help you and your healthcare team understand how diabetes is affecting your body</td></tr>
<tr><td>  </td><td>you and your healthcare team can make decisions about your health and your care</td></tr>
<tr><th colspan="2">What happens at a diabetes check-up?</th></tr>
<tr><td>  </td><td>At your check-up, a healthcare professional will do a blood test to check:
the average amount of sugar in your blood over the last 3 months - this is called your HbA1c</td></tr>
<tr><td>  </td><td>your kidneys are working</td></tr>
<tr><th colspan="2">What happens after a diabetes check-up?</th></tr>
<tr><td>  </td><td>Ask your healthcare team if you do not understand something.</td></tr>
</table>

Figure 8: Example of a health-related information about diabetes in easy language. Reproduced from Diabetes UK [154] with permission of publisher Diabetes UK.

Comparison between standard, plain and easy language

Table 16 shows the recommendation of a Covid-19 regulatory measure in standard language and translations into plain and easy language [155].

Table 16: Comparison between standard, plain and easy language

Language version	Example
Standard language	**§ 3 Mund-Nasen-Bedeckung** (1) Bei der Nutzung von Verkehrsmitteln des Öffentlichen Personenverkehrs und den hierzu gehörenden Einrichtungen und bei dem Besuch einer Verkaufsstätte in geschlossenen Räumen ist eine Mund-Nasen-Bedeckung zu tragen [131].
Plain language	**Das Tragen von Masken** Alle Menschen müssen im Nahverkehr, Einzelhandel und ähnlichen Einrichtungen geeignete Masken tragen [132].
Easy language	**Masken tragen** An vielen Orten muss man eine Maske tragen. Immer dann, wenn Sie keinen Abstand zu anderen Menschen einhalten können. Zum Beispiel beim Einkaufen oder beim Arzt. Im Bus und in der Bahn [155]. 

3.3.1.2.4. Experiences of publishers of CHI

Two of six publishers were able to offer insights into the implementation procedure of easy language in CHI. The remaining four publishers lacked experience with this particular language version, as they had not implemented it at the time of conducting the interviews. One publisher reported a lack of awareness regarding the difference between plain and easy language. Another publisher was unaware that texts in easy language require the supplementation of visual aids.

One publisher reported that, in accordance with the legally prescribed accessibility regulations, they are obligated to provide basic information in easy language. In order to meet this requirement, the publisher provides general information about the publisher, such as the publisher's goals, the process for selecting health information topics, and the composition of the publisher's team, on the publisher's website in easy language. In addition to the obligatory basic information, the publisher offered a CHI to a medical examination measure in easy language, downloadable as PDF.

The publishers reported some challenges when implementing easy language in CHI. One publisher highlighted the challenge of combining the criteria of easy language (e.g., wording, layout and content) with the criteria for evidence-based health information. Another reported challenge was presenting complex topics such as first aid interventions or risk communication of medical interventions in easy language, as this could results in an excessive demand by the target group.

> *„Was immer ein bisschen knifflig ist, ist die Risikokommunikation. Wie präsentiert man Zahlen? Was versteht die Zielgruppe noch? […]. Wir wollten auch mal was zu Erste Hilfe machen und da wurde es auch widergespiegelt. Also das überfordert vielleicht auch die Zielgruppe, wenn die Erste Hilfe machen müssen und in der Gesundheitsinformation alles genau drinsteht." (IP6)*

The evaluation process of CHI in easy language was described as being time-consuming and requiring additional organizational resources:

> *„Wir lassen das immer noch mal durch Menschen mit geistiger Behinderung gegenlesen, die auch Geld dafür bekommen. Aber das ist nicht immer leicht an so eine Prüfgruppen ranzukommen. Das muss ja alles organisiert werden." (IP6)*

One publisher described the search of suitable and self-explanatory images as a very challenging task. The publisher stated that commercial and freely accessible image databases often provide only limited options that do not reflect the actual diversity of the population. The attempt to break stereotypes in the representation of health topics was described as particularly difficult:

> *„Wir versuchen auch manchmal mit Klischees aufzubrechen, z.B. wenn wir über Depression reden, dass wir nicht immer ein Bild von einem jungen Mädchen nehmen, sondern auch mal von einem alten Mann. [...] Aber das ist wirklich schwierig, weil in diesen kommerziellen oder frei zugänglichen Datenbanken es diese Bilder leider nicht gibt […]. Also das ist ein ganz großes Thema, wo wir uns wirklich immer bemühen, aber einfach an unsere Grenzen stoßen.“ (IP6)*

Furthermore, the publisher reported that although there were initial internal concerns about the feasibility of developing CHI in easy language, it is now being produced effectively. However, awareness of this way of presenting information to the target audience remains limited.

3.3.1.2.5. Points to consider in case of implementation

Legal context of easy language

In Austria, there are no specific laws regulating the use of easy language. The UN-convention on the Rights of persons with disabilities, which Austria ratified in 2008, emphasized the need for persons with disabilities to be provided with accessible information on mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities [156]. However, the term easy language does not appear in this law.

An obligation to provide CHI in easy language can be derived from the E-Government Law (E-GovG) of 2004 (revised in 2016) and the "*Bundes-Behindertengleichstellungs-Gesetz*" (BGStG, Federal Equality Law) of 2006, neither of which formulate clear rules, but provide for the "best possible comprehensibility of documents" or a type of service that enables "equal participation" for all. The "*Barrierefreiheitsgesetz für digitale Anwendungen*" (Accessibility Law for Digital Applications) obligates companies to bring certain products and services in the field of information and communication technology that have been classified as particularly important for people with disabilities onto the market in accessible form only by 28 June 2025. However, even these laws do not use the term easy language ("*Leichte Sprache*").

The draft of DIN SPEC 33429, entitled „*Empfehlungen für Deutsche Leichte Sprache*", was published in March 2023. However, at the time of writing this thesis, no finalized DIN has been published.

Rules for easy language

Many rules of easy language have been provided by interest groups and organizations committed with providing accessible communication of CHI to consumers. In this thesis, the rules of Maaß (2015) are explained in more detail, because they are based on several sets of rules and are scientifically evaluated and specified. The main rules of easy language relate to the levels of character, word, sentence, text, typography and layout [153].

1. Character level

1) Special characters

In order to reduce grammatical complexity in easy language, it is recommended to use special characters, such as full stops and colons as well as question, exclamation, quotation and punctuation marks. Statements in easy language typically presented in short and simple sentences, each concluding with a full stop. Each statement should be formulated as a single

sentence. It is therefore recommended that commas be avoided in order to separate parts of sentences. However, colons are often used to emphasize lists and central statements, while quotation marks are used to mark direct speech. The media point is an alternative reading aid that can be used to break down long, complex compound words into their component parts. In contrast to the hyphen, media points avoid possible misunderstandings and have less impact on the word form [153].

2) Paraverbal and nonverbal signs

Easy language requires the redundant presentation of paraverbal and nonverbal signs to minimize the probability of important information being overlooked or not fully understood. Paraverbal signs encompass typographic and layout-related elements, such as bold print, indentation or the use of font colors and font size. Non-verbal signs can be presented in the form of diagrams, images or illustrations, for example. To illustrate, a particularly important information in a brochure could be emphasized in bold print and illustrated with an image simultaneously [153].

3) Numbers and digits

With regard to the use of numbers and digits, it is recommended to use Arabic instead of Roman digits ("*3*" instead of "*III*"). Numbers should also be presented as digits rather than as number words ("*1*" instead of "*eins*"). Historical dates should be avoided or simplified ("*vor langer Zeit*" instead of "*1800*"). Large numbers and percentages should be checked individually for relevance. If they are important to the content of the text, they should be retained and, if necessary, illustrated with visual aids such as diagrams. However, this may be helpful in different ways depending on the target group; some readers may need additional support to understand such visualizations [153].

<u>2. Word level</u>

1) Use of basic vocabulary

It is recommended that technical terminology be replaced by more general terms from the basic vocabulary, unless the technical terminology is essential for understanding the text. In such cases, these terms should be explained or supplemented with images [153].

2) Use of words that are as short as possible

It is recommended that the use of concise vocabulary be prioritized, as the processing of lengthy and complex words can impede the reading process. Readers need more time to

process words with many syllables than shorter, monosyllabic words. This challenge is particularly pronounced for those with limited reading experience compared to those who are more proficient [153].

3) Avoidance of technical and foreign words

The use of technical and foreign words should be avoided and replaced by appropriate terms, wherever possible. However, if there is no appropriate alternative word, and especially if the technical or foreign term has a central meaning in the text, it is acceptable to retain the words and explain them [153].

4) Use of known abbreviations

Font-based abbreviations such as "*d.h.*" or "*usw.*" should be avoided, as they are only correctly interpreted by individuals with experience in reading such texts. Conversely, it is acceptable to use familiar common abbreviations such as "*WC*" or "*LKW*", as they do not affect the comprehensibility of texts in easy language [153].

3. Sentence level

There exists several rules and techniques to simplify sentences in easy language [153]:

1. Use of verbs instead of nouns.
2. Use of active sentences instead of passive and impersonal sentences. It should be clearly stated who is doing what.
3. Use of the nominate case („*die Behandlung des Arztes*") instead of the genitive case („*Arzt's Behandlung*").
4. Use of a clear and simple sentence structure (subject-predicate-object).
5. Use of one sentence per statement.
6. Complex sentence structures and subordinate clauses are split into individual, simple sentences.
7. Use of indicative („*er kommt später*") instead of subjunctive („*er sagte, er käme später*").
8. Use of present tense („*er ist gekommen*") instead of simple past („*er kam*").
9. Use of easily understandable and generally familiar metaphors.
10. Avoidance or explanation of more complex visual expressions
11. Avoidance of negation. For example, the phrase "*er aß*" should be replaced through "*er hat gegessen*". The phrase "*Wir haben heute keinen Sport gemacht*" should be formulated as "*Wir haben heute nicht Sport gemacht*." or „*Das haben wir heute nicht gemacht: Sport machen*."

12. Use of common rather words (“*keinen Hunger haben*” or “*Körper*”) instead of rare words (“*appetitlos*” or “*Bewegungsapparat*”).

4. Text level

There exists also a number of rules for easy language at the text level [153]:

1. Typographical aids, such as glosses, headings, highlighting and images can support the structure of the text.
2. Texts in ease language should include only the most relevant information aiming not to overload the text.
3. Texts in easy language should use the same words for the same facts, e.g., use of “*Tablette*” or “*Pille*”.
4. Use of keywords in the margins or in subheading.
5. Texts in easy language can be made more understandable by using referrals, such as adding explanations or glossaries.
6. Texts in easy language should not replace the original text, but supplement it.

5. Typography and layout

Use of images

Images play an important role in easy language, providing a visual representation that supports the comprehension of challenging or pivotal concepts. It is essential that images are not just decorative; they must support the content. Images structure the text and emphasize key content by supporting headings and repeating key information. Complex concepts can be illustrated using images such as photographs, diagrams or pictograms, similar to the way in which images and text work together to aid understanding in technical texts. However, the targeted use of images is challenging, as the images need to match the content of the text and be tailored to the heterogeneity of the target audience [153].

Risk communication in easy language

The risk communication in easy language is more restricted than in plain language. However, scientific studies are lacking regarding the optimal presentation of numbers, risks, and probabilities in evidence-based health information in easy language. In general, it is not recommended to present numbers in easy language texts as they can be difficult to understand for many people. Instead of numbers, comparisons and imprecise statements should be used (Table 17). However, communicating numbers and probabilities can facilitate the

understanding of disease risks and support shared decision-making, and should not be avoided completely [150, 151].

Table 17: Risk communication in easy language [157]

	Not recommended	Recommended
Example 1	17.895 people	Many people
Example 2	15%	Some or a few
Example 3	Seven children	7 children

Visualizations in easy language

CHI in easy language should be visualized in an appropriate manner, i.e. images should serve as a function within the text, rather than serving for purely decorative purposes. It is important that the target group of easy language is not overwhelmed by excessive visualizations. Instead, visualizations should be selected to enhance the understanding of medical information, for example through the use of a picture of a dialysis machine. Anatomical drawings can be used and labelled to illustrate the placement of body parts, whereas the use of children's drawings is not recommended in CHI targeted to adults. In addition, images should not be used to guide the text. This function should be performed by layout elements, for example through the use of colors or columns [151].

The use of tabular data, graphical representations, and diagrams can support the comprehension of numerical relationships. However, the level of understanding or knowledge depends on the specific target group and needs to be assessed on a case-by-case basis [151].

Machine translation tools

As with plain language, machine translation tools are also available for translating text in easy language [158-160]. However, at the time of writing the thesis, no scientific study could be identified that evaluated the quality of such tools in the context of health information (status November 2024).

Questionnaires in easy language

To enable people with limited literacy skills to participate in scientific surveys, providing questionnaires in easy language is just as important as developing CHI in easy language [161, 162]. However, questionnaires in easy language are currently available only to a limited extent [161, 163, 164].

A psychometric analysis indicated that translating a self-efficacy questionnaire into easy language did not compromise its methodological properties in comparison to the original version of the questionnaire. The easy-language version met all standard psychometric quality criteria, including internal consistency (Cronbach's Alpha = 0,84), adequate item difficulty, and discriminatory power. Table 18 provides a comparison of illustrative items from the original version alongside their easy language translations [161].

Table 18: Example questionnaire items in original and easy language version [161]

Original item	Item translated in easy language
Wenn sich Widerstände auftun, finde ich Mittel und Wege mich durchzusetzen	Gehen Sie Ihren eigenen Weg, auch wenn es manchmal schwer ist?
In unerwarteten Situationen weiß ich immer, wie ich mich verhalten soll.	Manchmal passieren Sachen, die vorher nicht geplant waren. Wissen Sie dann immer, was Sie tun sollen?
Wenn ein Problem auftaucht, kann ich es aus eigener Kraft meistern.	Können Sie ein Problem alleine gut lösen?

Labelling of CHI in easy language

Labels or quality seals highlight texts written in easy language and help capture the attention of the target group. The Easy-to-Read logo (Figure 9) of the Inclusion Europe association is currently the most widely used label for marking texts in easy language. The use of this logo is permitted without a separate authorization, if publisher follows the corresponding guideline and integrate the following reference text [165]:

"© European Easy-to-Read Logo: Inclusion Europe.
More information at www.inclusion-europe.eu/easy-to-read".

Furthermore, it is recommended that the logo be placed in a prominent position on the CHI.

Figure 9: Easy-to-read logo. Reproduced from Inclusion Europe [165] with permission of publisher Inclusion Europe.

Review of CHI in easy language

As outlined in the previous chapter '*Points to consider in case of implementation - Review of CHI in plain language*', the same issues should be considered when developing CHI in easy language.

3.3.1.3. Sign language

3.3.1.3.1. Definition

Sign language (in German "*Gebärdensprache*") is a form of visual language used primarily by people who are deaf or hard of hearing. Sign language uses a range of non-verbal communication techniques, including movements of hands and arms, facial expressions, posture and gestures to convey meaning and facilitate communication. In contrast do auditory stimuli used in spoken languages, sign languages are based on visual stimuli. However, sign language is not the same as pantomime or non-verbal communication. Furthermore, sign language is no universally standardized language. As with spoken languages, there are many different forms of sign language that differ across countries. Every country has its own sign language and each sign language has its own rules, vocabulary, grammar and syntax. In some cases, there exists also regional difference with specific dialectical and sociolectical variations, such as differences between younger and older generations [166-169]. Overall, there are approximately 300 different forms of sign language globally [170]. For example, different signs in Pakistani, British, and American Sign Language for the words 'female' and 'male' are shown in Figure 10.

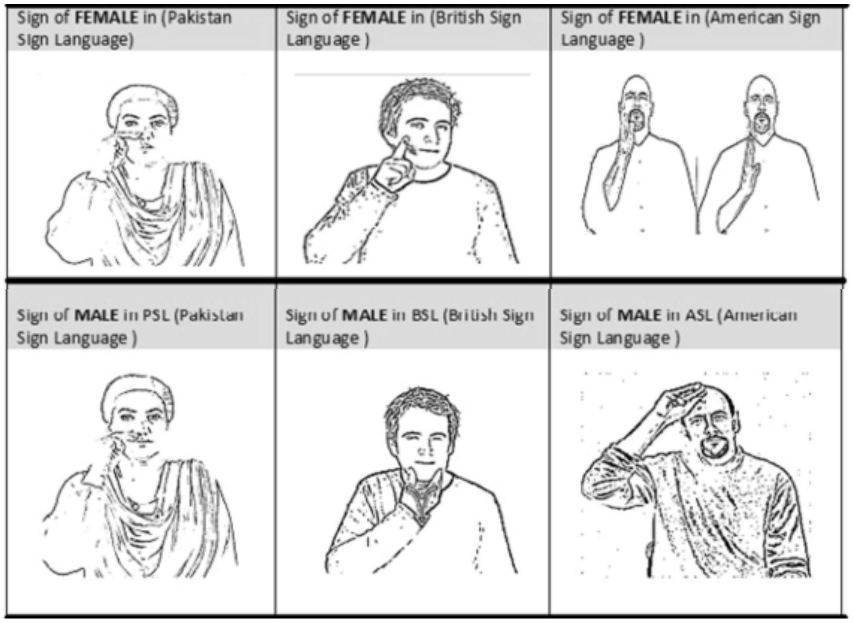


Figure 10: Signs for 'female' and 'male' in different sign languages. Reproduced from Farooq et al. [171] with permission of Springer Nature.

The Austrian sign language was formally recognized as an independent language in the year 2005 and subsequently included into the Austrian Federal Constitution [166]. Although sign language is not universal, there exists an international communication tool called International

Sign that is regularly used at international conferences and discussions with participants who do not use the same sign language. However, International Sign has a limited lexicon and is not as conventional or complex as natural sign languages [169, 172].

Deaf people primarily use sign language as their first language, rather than an oral language [173]. Many deaf children experience delays in their language acquisition, primarily due to their limited access to everyday language, which is the main source of vocabulary acquisition for their hearing peers [174]. Deaf children typically possess approximately half the vocabulary size of their hearing peers [175]. However, deaf children who have earlier access to a sign language community have been observed to develop improved vocabulary skills [176]. In particular, deaf children who are exposed to sign language prior to the age of six months have been shown to develop vocabulary at rates comparable to their hearing peers [177]. Moreover, similar brain activation patterns have been identified in deaf children who have access to both oral and sign language from an early age, as observed in hearing peers [178].

3.3.1.3.2. Target group

The main target group for sign language are people who are deaf or hard of hearing. This includes people with congenital or acquired hearing impairments and people with speech impairments who are unable to speak due to physical or neurological limitations. Additionally, relatives, friends and deaf professionals also use sign language to communicate with people who are deaf or hard of hearing. According to the World Federation of the Deaf, the global population of deaf individuals who use sign language exceeds 70 million [179].

3.3.1.3.3. Examples

In order to provide accessible access to CHI for individuals who are deaf or hard of hearing, publishers of CHI need to pay attention to specific linguistic concepts for this distinct patient population. The following section illustrates some examples of how CHI can be designed for this target group.

CHI videos with sign language interpreters

The embedding of sign language interpreters within CHI videos can promote an accessible health communication. The dissemination of such videos can be achieved through websites, mobile apps and social media platforms. Bilingual-bimodal approaches offer a dual approach, combining both spoken and signed languages in parallel. Alternatively, videos can be created that exclusively feature the sign language interpreter, delivering the content in sign language. This option is particularly suitable for platforms or content that is specifically designed for deaf people, offering a clear and focused communication.

Subtitled and captioned health information videos

If the incorporation of sign language interpreters into videos is not feasible, a useful alternative could be the addition of subtitles and captions. This option improves accessibility for deaf and hard-of-hearing individuals by providing the spoken word and relevant auditory information in text form. Numerous platforms, such as YouTube, offer automated captioning, where AI-based speech recognition to convert spoken language into text in real time.

Digital animated sign language avatars

Another technological innovation in the field of sign language is the provision of digital and animated avatars in electronic media (Figure 11), aiming to facilitate accessible information in situations where human interpreters are not available. These avatars use AI-technologies such as machine learning to translate spoken or written language into sign language and display it in real time. The software then translates this data into sign language. The digital avatar performs the corresponding gestures by imitating hands, facial expressions and body language. AI-models learn from large amounts of sign language data to produce precise and natural movements. These digital avatars can be employed across a variety of electronic media, including websites, apps and social media platforms [180-182].

Figure 11: Animated avatar using sign language. Reproduced from Sign Time [183] with permission of publisher Sign Time.

One possible implementation of sign language in CHI is the integration of additional sign language avatars in package leaflets of pharmaceutical drugs. Users can access a linked website with their smartphone by scanning the QR code on the leaflet, where they can find animated product information. There are explanatory videos with and without sign language interpreters [184].

CHI in SignWriting

SignWriting (in German "*Gebärdenschrift*") is a writing system that was developed with the specific purpose of representing sign languages in written form. In 1974, the American Valerie Sutton, developed a system of writing that enables the recording of the movements and positions of the hands, as well as facial expressions and body posture. The original purpose of SignWriting was to serve as a means of notation for dances. In contrast to sign language, SignWriting is a universal form of communication utilizing the same symbols globally. SignWriting uses iconic signs that directly represent the movements and shapes of the hands [185]. Figure 12 represents an illustrative example of a CHI in SignWriting, specifically instructions for handwashing.

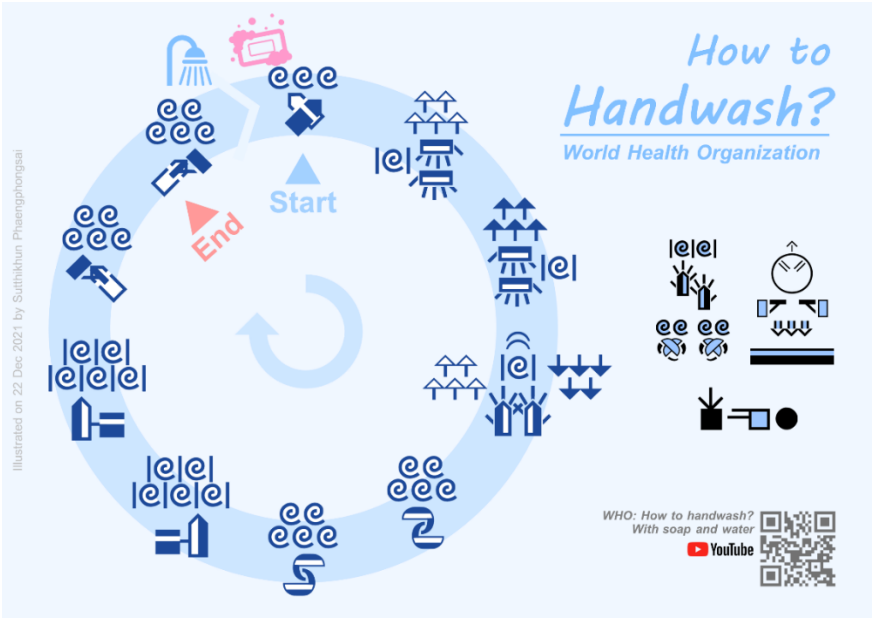


Figure 12: Instructions for handwashing in SignWriting. Reproduced from World Health Organization [186]. The figure was published under the terms of the Creative Commons CC BY license 4.0 (http://creativecommons.org/licenses/by/4.0/) via Wikimedia Commons.

Clinical assessment tools in sign language

The most clinical assessment tools, such as screening instruments or patient questionnaires, are designed for the use of the general population who speak oral languages. They do not, or only to a limited extent, consider the specific needs of people with impairments. To improve the quality of healthcare for people who are deaf or hard of hearing, it is beneficial to translate and validate important clinical assessment tools, particularly those related to mental and behavioral health as well as pain management. Customizations of clinical assessment tools into sign language refer to readability, wording, and regional differences in signing words or phrases as well as length of the tool. The use of translated clinical assessment tools for sign language users can be very helpful as an objective source of supplementary information in a clinical interview between health care professionals and deaf patients [187, 188].

Visual language

Visual communication tools can be particularly helpful in situations where people speak different languages. Picture dictionaries are such a form of visual communication tools that are already being implemented in practical settings. A picture dictionary is a universal, wordless communication supporting tool which contains various simple and comprehensible symbols, pictograms, and photos that cover different areas of life, such as health concerns, hygiene, clothing and nutrition (Figure 13). By simply pointing to the appropriate picture, it is possible to

communicate without words and convey important information quickly and easily. This is particularly important in situations where fast and clear communication is required, for example when requesting a remedy for diarrhoea or an insect repellent. The picture dictionary was originally designed to support travelers, but is now primarily used to assist refugees. However, the use of picture dictionaries can also be useful for other target groups, which have difficulties in expressing themselves verbally, such as stroke patients, patients with dementia, aphasia or autism as well as deaf people and deaf-mute people. Picture dictionaries can be created in digital form (as an app) or as a printed version [189].

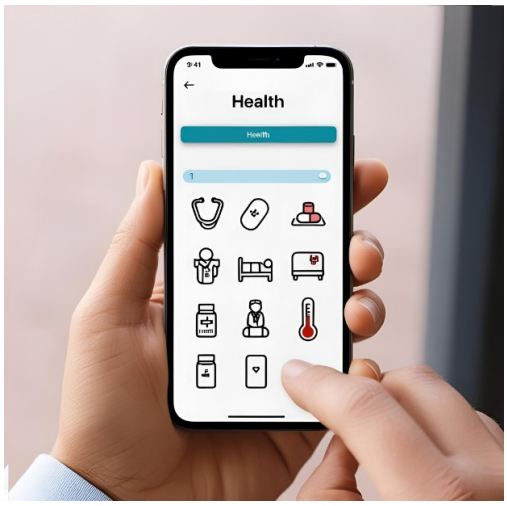


Figure 13: Picture dictionary. (Prompt: Eine Hand hält ein Smartphone. Bildschirm des Smartphones: Zeigt eine App mit dem Titel "Health”. Symbole auf dem Bildschirm: Gesundheitsbezogene, einfache, schwarze Strichzeichnungen, z.B. Stethoskop, Tablette, Krankenwagen, Arzt mit Kittel, Canva, 13.05.2025, www.canva.com)

Furthermore, visual aids can support deaf or hard-of-hearing people in the context of pharmaceutical administration, where there is often a high prevalence of misunderstandings regarding dosages, the interpretation of unfamiliar or ambiguous terminology, and the provision of multiple documents. In order to minimize the risk of prescribing errors among this target group, specific visual aids for this linguistic minority group, such as charts, drawings, calendars, or the indication of precise dates for taking medication, should be designed [187].

3.3.1.3.4. Experiences of publishers of CHI

Only a few of the publishers interviewed could report experiences with creating CHI in sign language at the time of the interviews. One publisher explained that due to legal requirements, basic information on a website must be provided in sign language, similar to easy language. In this context, the publisher has created two videos in sign language that describe information about the publisher and explain how to navigate on the website. The development of comprehensive CHI in sign language is not planned due to limited resources.

Another publisher has announced a collaboration with an institution that offers videos in sign language. The future intention is to embed these videos on the publisher's website, with the objective of enhancing accessibility for deaf and hard-of-hearing individuals.

As the majority of the publisher's lack experience in the implementation of sign language in CHI, no particular challenges in the preparation of CHI in sign language could be identified at the time of conducting the interviews.

3.3.1.3.5. Points to consider in case of implementation

Labelling of CHI in sign language

The logo of sign language is an internationally recognized symbol that is used to identify places, services, products or information materials that are accessible to people who use sign language. The symbol typically consists of a representation of two hands forming a sign (see Figure 14). This symbol is often displayed in public institutions, in locations or on information materials (e.g., websites or videos) that offer sign language interpreters. The logo serves to promote the visibility and inclusion of deaf and hard-of-hearing people by signaling that sign language is supported in these settings.

Figure 14: Logo of sign language. Reproduced from Iconduck with MIT-license.

Machine translation tools

Machine translation tools have the potential to support the development of subtitled and captioned health information videos and digital animated sign language avatars. However, it is important that publisher of CHI consider some points when utilizing AI-tools for the development of CHI in sign language.

CHI in sign language should consider national sign language rules, necessitating the training of AI-tools on large datasets comprising national sign language vocabulary, grammar and syntax. These datasets must contain a variety of examples to ensure accurate representation of linguistic variations [190].

AI-tools are currently insufficiently developed to fully capture national sign language standards, as well as cultural characteristics and emotional nuances of sign languages. It is therefore imperative that translations generated by machine translation tools are checked by human translators with experience in this field, ideally from native signers who are also medically qualified [190-192].

Captioning in CHI videos

The inclusion of automatic captioning of spoken language with accurate (correct words) and timed (properly synchronized) captions is imperative, particularly for live-streaming videos. The absence of captions in live-streaming videos can lead to feelings of isolation and frustration for deaf signers, and the process of searching for captioned videos of similar content can he highly time-consuming. Mack et al. (2020) demonstrated a significant correlation between hearing loss and the inability to consume uncaptioned content, delayed access to news, and a sense of disconnection from popular culture [193].

In case of CHI videos addressed to children, it is recommended that the vocabulary and syntax of subtitles and captions be customized in order to meet the needs of deaf and hard of hearing children. The vocabulary can be simplified by avoiding abstract or figurative meanings when the intention of the audiovisual text is not to acquire such vocabulary. In the case of difficult captioned vocabulary, it can be highlighted in bold and underlined, and reduced in subtitling speed. The syntax can be made more straightforward by using a simple phrasal structure (subject-verb-object) and avoiding subordinate clauses and the use of coordinate clauses [194].

Accessible design of CHI for deaf users

Given the prevalence of low literacy among deaf individuals [174-176], it is recommended to design CHI in a user-friendly manner. In particular, websites should be customized for ease of navigation, with video content that is straightforward to comprehend, incorporating short open captions, and incorporating interactive and visual elements, such as graphics and animations [187, 195]. However, publishers of CHI can customize the content to align with the health literacy levels of deaf signers, i.e. using more abstract signs for deaf individuals with higher levels of health literacy [196].

Although sign language is the preferred method of communication among deaf users, it is not considered necessary to translate all information into sign language. An introductory sign language video focusing on complex health-related information in sign language is preferred and sufficient, with written text providing additional support to facilitate understanding [196].

In addition, it is essential to assess the usability of websites from the perspective of the target audience. User feedback should be incorporated into the design process to ensure the effective delivery of services and the satisfaction of users [187].

Accessibility requirements of CHI in sign language

In order to ensure the accessibility of digital media for individuals who are deaf or otherwise have trouble hearing the dialogue in audio-visual material, certain national and EU standards and guidelines have been established. In Austria, such legislation includes for example the Disability Equality Acts (*Bundes-Behindertengleichstellungsgesetz*) and the Accessibility Act for digital applications (*Web-Zugänglichkeits-Gesetz*).

Moreover, the WCAG offer dedicated points to consider in case implementation materials in sign language, such as technologies that present synchronized media information and related techniques for providing sign language interpreters in video streams. These guidelines offer a comprehensive set of recommendations for the design of videos featuring sign language interpreters, including crucial details such as the optimal display of the interpreter, the incorporation of additional visual information in sign language videos, the color of the interpreter's attire, the background color of the video, and the angle of the interpreter's face towards the camera [197].

3.3.1.4. Culture-sensitive language

3.3.1.4.1. Definition

Culturally sensitive CHI provides accessible and tailored content that address the specific needs of individuals from diverse cultural and ethnic backgrounds. Cultural sensitivity involves an awareness and consideration of the diverse values, beliefs, and experiences of ethnic minority groups. It is defined as "*the ability to recognize, understand, and respond appropriately to the beliefs, values, norms, and behaviors of people from cultural or ethnic groups different from one's own*" [198].

Incorporating cultural differences into health communication enhances its effectiveness and relevance. Therefore, culturally sensitive health communication can be understood as "*the deliberate and evidence-based adaptation of health messages to align with the cultural background of the intended audience, with the aim of increasing knowledge, supporting informed medical decision-making, and improving the persuasiveness of health promotion efforts*" [199]. The process of culture-sensitive health communication is illustrated in Figure 15.

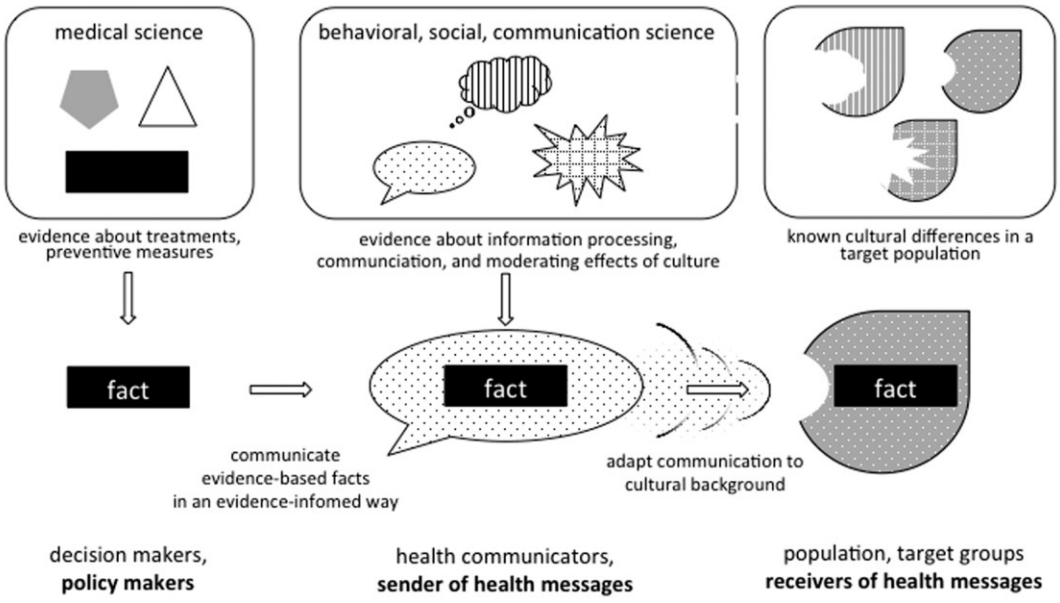


Figure 15: Process of culture-sensitive health communication. Reproduced from Betsch et al. [199] with permission of publisher SAGE Publications.

The process shows that culturally sensitive health communication is an interdisciplinary process between medical, behavioral, social and communication science. The findings from medical science form the basis of evidence-based health information, which then informs behavioral, social and communication science of the process of message and information design. The task of health communicators is to adapt the evidence-based facts to the individual psychological characteristics and cultural background of the users.

The present thesis focuses only on the cultural customization of medical concepts for the development of evidence-based health information. The customization of behavioral, social and communication issues is not within the scope of this thesis.

People with a migration background are likely to possess differing perceptions of disease patterns and health risk factors in comparison to the general population in the target country. These perceptions may be unknown to healthcare professionals in the target country [200].
For example, the Western medicine assumes that biological, psychological, and social factors interact with each other and can precipitate illness. However, in numerous cultures, illness is not conceptualized within the bio-psychosocial framework but rather as a form of ‘punishment from God’ or a ‘test of faith’ [201]. For example, the disease concept of the “evil eye” is a widespread belief in many cultures. It assumes that a person’s gaze, whether intentional or unintentional, can cause harm. This phenomenon often occurs through the transfer of negative energy from one person to another. In many cultures, the ‘evil eye’ is seen as the cause of physical or emotional distress, illness, or misfortune. Those believed to be affected by the ‘evil eye’ are often thought to experience physical complaints immediately after the envious gaze, such as headache, fatigue, dizziness, concentration problems, unexpected childhood illness, accidents, or even death. In some cultures, is can also be used as an explanation for failure, infertility or problems with children. It is often assumed that infants and young children are particularly vulnerable to the ‘evil eye’, due to their perceived lack of resilience. To protect against the ‘evil eye’ there are rituals and symbols in various cultural traditions, such as the help of traditional healers, preventive measures such as wearing amulets, dressing children in unclean clothes, painting household items blue, ritual words and wearing blue or red shirts [201].
Consequently, different perceptions of health and illness may result in inequalities in migrants’ access to professional advice, preventive and treatment interventions [200].

The translation of CHI into additional languages is an important measure to meet the needs of people with different linguistic backgrounds. However, the provision of multilingual CHI alone is insufficient to fulfil the information needs of people with different cultural or ethnic backgrounds. The customization of CHI in a culturally sensitive language requires more than just the linguistic translation of the content [202]. Culturally sensitive health information is relevant in situations where there are cultural barriers or discrepancies in knowledge about the healthcare system, diseases or treatment options. Such barriers may arise from differing perceptions and attitudes towards health issues within a given society or between different cultures [203-206]. Furthermore, adapted high-quality translated culture-sensitive CHI are significantly more useful than standard translated CHI for patients with a lower level of dominant society immersion than patients with a higher level of immersion [93].

3.3.1.4.2. Target group

Culturally sensitive CHI should address individuals from diverse cultural and ethnic backgrounds who may have specific linguistic and communication needs. The primary target group for such information are individuals with a migration background. However, it is important to note that ethnic minority groups within a country or religious community can also benefit from culture-sensitive CHI. For example, in the case of religious regulations of nutrition and medical treatments. Moreover, the provision of culturally customized CHI can be particularly beneficial for indigenous populations in the event of environmental changes or adversities, such as war or pandemics. In such situations, it is important that the information is adapted to the current circumstances, such as the availability of medicines or the occurrence of communicable diseases [207, 208].

3.3.1.4.3. Examples

Multilingual CHI

The provision of CHI in additional languages ensures that all users, regardless of their native language, have access to relevant health information. Multilingual CHI enables individuals who speak different languages to engage in discussions and achieve a better understanding of health-related information when presented in their native language. They facilitate the communication between people in the absence of interpreters, thereby enhancing the accessibility and comprehension of important health information for multicultural communities. Furthermore, the provision of CHI in multiple languages ensures more equitable and effective dissemination [209].

Moreover, people with a migration background prefer CHI in their first language. The benefits of multilingual CHI are manifold. Firstly, it allows people with limited knowledge of the local language to access the healthcare system at an early stage. Secondly, it ensures that they are fully informed about medical treatments that are necessary or recommended for them. Thirdly, it can reduce the burden on healthcare staff and the healthcare system. For instance, in times of crisis, such as a pandemic, it is beneficial for the entire population when all population groups are able to understand and comply with rules and measures [202, 210].

There are several possibilities to prepare CHI in a format with multiple languages, both for print and electronic media. Such formats can help to avoid potential misunderstandings in conversations between people with different linguistic backgrounds that can arise when only monolingual health information is available. For example, such formats can be useful in families where the son is speaking German and the mother Turkish, or in conversations between health care professionals and patients.

The following examples illustrate some methods of presenting CHI in additional languages:

- **Column layout:** Two or several languages are displayed side-by-side in a two- or multi-column layout (Figure 16).
- **Page layout:** Each language presented on a separate page, e.g. English on page 1, French on page 2.
- **Info-boxes:** Key health information are presented in separate info-boxes in several languages.
- **Overview page:** An overview page summarizes the most important information in several languages.
- **QR codes for audio files:** Written information are linked to audio files via QR codes including different translations of the content.
- **Interactive PDFs:** Electronic CHI, such as PDFs, are designed to be interactive to make it easier to use. Hyperlinks or buttons enable users to navigate between different language versions of the document. A drop-down language selection on the initial page can also permit users to switch directly to the desired language and access the relevant information.

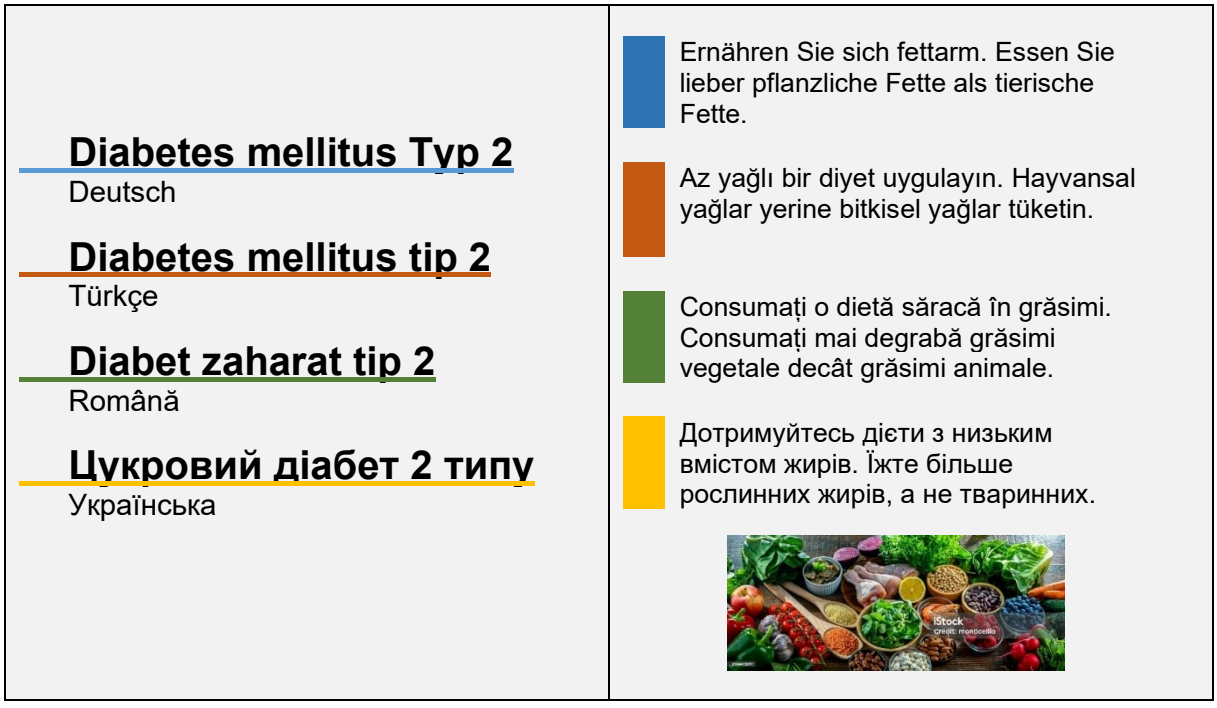


Figure 16: Example of a multilingual health information brochure about T2DM

Relevant health topics for persons with a migration background

People with a migration background require information to specific health topics in comparison to indigenous people. A needs assessment survey conducted in Austria in 2021 revealed that individuals with a migration background expressed a particular interest in health information pertaining to the local health care system, mental health (in both women and men), women's health, children's and youth health and nutrition [202].

People with a migration background frequently encounter specific information deficits regarding local healthcare conditions. Numerous studies have indicated that they often lack knowledge about where to seek assistance for health concerns and are unaware of available services and standard practices. They are insufficiently informed about the healthcare system, care pathways, local health services, counseling centers, as well as the legal framework governing healthcare provision. Moreover, there is often limited information regarding the coverage of treatment costs by health insurance, as well as affordable alternatives to prescription medications [201, 202, 211, 212]. Therefore, it is imperative that publishers of CHI ensure the availability of fundamental guidance on the rights and support mechanisms within the local healthcare system.

The provision of culturally sensitive CHI is of particular importance in the context of mental health, especially for some ethnic minority groups, because they have a limited or differentiated knowledge about mental disorders. In some cultures, mental disorders are frequently stigmatized and associated with shame. People often do not seek psychiatric or psychotherapeutic help, due to skepticism about available treatment options, lack of information or fear of social stigmatization. In addition, there is often a lack of awareness about the existence of specialized healthcare professionals and available treatment options that may be unknown in their countries of origin [211-216]. Moreover, individuals with a migration background are more likely to experience mental disorders than the general population, which can be attributed to migration-related stress factors [217-220]. For instance, attitudes and perspectives towards suicide are often deeply rooted in cultural and religious norms. In some cultures, suicide is seen as a shame for the family. In many countries, suicidal behavior is strongly condemned and, in some countries, even prohibited by law. For example, attempted suicide was, until recently, a criminal offence in India until 2017 and in Singapore until 2020 [221, 222].

Another problem is, that some disorders are not recognized as a disease in many countries, such as addictions. An addictive behavior is often seen as weakness of will or self-inflicted harm, or even as a violation of family honor. Culturally sensitive CHI should educate that mental disorders or disorders that are perceived as shameful, such as AIDS or addictions, are recognized as treatable illnesses in Western countries. They should also inform people that there are professional treatment options and that relapses are possible during or after treatment. Those patients should be aware that they will continue to receive support and can return to their therapists at any time [201, 212].

The Austrian needs assessment survey 2021 showed that both men and women with a migration background are interested in specific women's health topics, such as pregnancy. Especially for girls and women with a migration background, it would be beneficial to produce culturally sensitive CHI, which specifically addresses topics such as the gynecologist visit. Such materials could include information about the typical procedure of a visit to the gynecologist, such as presentation of the woman at the gynecologist's chair, information about the female body, and details about health services and resources are available to girls and women in the country. It would also be beneficial to address taboo topics such as female genital mutilation and contraception in an open and honest manner. However, it is of the utmost importance to employ a tactful approach to facilitate discourse on these subjects, which are often perceived as sensitive [202, 210, 223]. Such an approach has the potential to raise awareness of these issues, as well as to reduce the barriers faced by affected women in accessing important health information.

Culture-specific concepts of diseases and treatment options in the target country

CHI in a culturally sensitive language should include information about the understanding of health and illness in the target country. For instance, in many Western countries, such as Austria, the understanding of health and illness is based on the bio-psycho-social model of health. This model stands in contrast to other cultural and traditional concepts of illness, which emphasize solely on physical or spiritual causes of diseases. The understanding of regional disease concepts may help to close the gaps in care that often arise due to cultural differences, can improve the utilization of healthcare services and the acceptance of medical recommendations.

Cultural eating traditions

People have different eating habits, traditions and preferences, which are often strongly culturally influenced. Specific religions have particular dietary rules and regulations. For instance, Muslims do not eat pork, Hindus avoid beef and many Buddhists practice a form of vegetarianism. It is important that these cultural differences are adequately reflected in CHI.

In the case of formulating dietary recommendations, it is important to familiarize with typical eating habits and traditions of the culturally diverse target group. Culturally sensitive food lists can be a valuable tool in the prevention and treatment of disease with a strong correlation to dietary habits [224].

Table 19 illustrates an exemplary culture sensitive food list, which lists a representative sample of typical Chinese foods and their respective nutrient content compared to alternative typical Western foods.

Table 19: Comparison of nutrition content of typical Chinese foods and Western alternative foods [225]

	Culture	**Food**	**Carbohydrate (gram)**	**Calories**
Cooked starches	Chinese	Lai-fun	44	190
	Western alternative	Barley	44	193
	Chinese	Lima beans	39	217
	Western alternative	Spaghetti	39	192
Fresh fruits	Chinese	Pomelo	18	71
	Western alternative	Apple	19	72
	Chinese	Persimmon	8	32
	Western alternative	Plum	8	36
Cooked vegetables	Chinese	Lotus root	15	60
	Western alternative	Carrots	16	70
	Chinese	Gourd	25	100
	Western alternative	Potato	22	93

Culturally sensitive food lists can be provided for people with different diseases to specifically support their diet in the target country. For example, publisher of CHI can list and compare the glycemic index of typical local foods (Table 20).

Table 20: Glycemic index of typical Chinese and Austrian foods [226-228]

Glycemic index	Chinese food	Austrian food
Low glycemic index	Green Bean Soup	Lentil soup
	Chinese Herbal Jelly	Apple puree
	Egg Tart	Curd cheese strudel (*Topfenstrudel*)
	Fried Rice Vermicelli in Singapore-style	Cabbage noodles (*Krautfleckerl*)
Moderate glycemic index	Baked Barbecued Pork Puff	Puff pastry ham croissant (*Blätterteig Schinkenkipfler*)
	“Mai-Lai” Cake	*Gugelhupf*
	“Pineapple” Bun	Butter brioche or cinnamon bun
	Glutinous Rice Ball	*Grießnockerl*

Furthermore, it is recommended that culture sensitive dietary guidelines pertaining to foods with a low glycemic index be incorporated, encompassing the reduction of sugar intake through the use of natural sweeteners, the augmentation of fiber consumption through the incorporation of nuts, seeds, and whole grains, and the incorporation of protein-rich ingredients. Such dietary lists can provide support to patients diagnosed with diabetes mellitus in the effective self-management of their blood sugar levels.

Similarly, useful are list of foods with low in sodium for people with hypertension, list of foods low in calories and high in nutrient for people with overweight and obesity, list of foods with low in saturated fat and cholesterol for patient with cardiovascular diseases or list of foods low in potassium, sodium, protein and phosphate for patients with kidney diseases.

Halal Medicine

In accordance with Islamic law, Muslims are obliged to adhere to religious values when consuming food and beverages, as well as when taking pharmaceuticals. There is a distinction made between permitted (*halal*) and forbidden (*haram*) substances. Many substances and processes used in the manufactures of pharmaceuticals do not comply with halal regulations. For instance, cough syrups containing alcohol or capsules containing pork gelatin, substances that are forbidden for many devout Muslims [229, 230]. In order to address the needs of this specific cultural group, publishers of CHI can provide lists or directories of halal-certified products.

Visual language

Visual communication tools represent also an appropriate customization option for CHI targeted to people with different linguistic and cultural backgrounds. Examples of visual language are provided in the chapter of *Sign language - Examples: Visual language*.

3.3.1.4.4. Experiences of publishers of CHI

Translation in additional languages

One publisher reported that all content on a website has been fully translated into English and is accessible via a dedicated domain. These translated CHI resources are only available in digital format; printed versions are not translated. In collaboration with another institution, some CHI are also translated into four additional languages and made available on another website. Three other publishers stated that they have not yet been able to produce translations of CHI. Upon demand as to the reason for the absence of translations into other languages, one publisher responded:

> „*Da muss ich zugeben, nein, Übersetzungen haben wir nicht. Aber ich glaube, das scheitert bei uns einfach an den zeitlichen und personellen Ressourcen. Da kämpfen wir eh immer.“* (IP3)

Another publisher was unable to report any experiences with translations into other languages at the time of the interview, as the content of the website had just been translated in collaboration with an agency. The publisher emphasized that only basic information and essential content on the website are translated, which is sufficient in the publisher’s opinion. According to this publisher, people with a migration background often use machine translation tools to translate health information in other languages, indicating that such tools are very helpful.

However, the use of machine translation tools in the process of translating CHI into additional languages was also discussed by other publishers. The discussion highlighted both advantages and disadvantages. One advantage is the rapid availability of translations, which can be accessed with a single click. Furthermore, the continuous improvement of translation quality was highlighted as a further advantage. The disadvantages of machine translation tools include occasional misinterpretation of content, low precision, and inadequate formulation of medical terminology in layman´s terms. Such translation errors are typically identified only by human experts. Consequently, some experts considered a hybrid approach to translate health information, as current AI translation systems are not yet capable of fully replacing human translators. Several of the interviewed publishers emphasized the importance of human review and quality check of machine translations to ensure high-quality CHI, particularly by native speakers or certified healthcare interpreters.

„Künstliche Intelligenz (KI) ist ein ziemliches Hot Topic, z.B. auch was die Übersetzung angeht. [..] Die Systeme sind alle viel cleverer geworden, als sie es noch vor ein paar Jahren waren. […] Allerdings, braucht es immer noch einen Menschen, der drüber liest, weil die Satzstruktur, die Inhalte, die sind wohl noch nicht perfekt und gerade eine gute Patienteninformation, auch wenn sie evidenzbasiert ist, hat ja ein ganz feines Wording, da müssen wir manchmal über jedes Wort nachdenken […], das schafft die KI noch nicht." (IP6)

However, one publisher highlighted that translations produced by professional interpreters are not always free from errors, and that an additional review by a native speaker is recommended:

„Also wir haben zum Beispiel professionelle zugelassene Dolmetscher für den Gesundheitsbereich, die haben wirklich Ahnung von Übersetzungen. Und weil wir trotzdem merken, dass immer wieder Fehler drin sind, lassen wir das auch immer noch mal von einem Muttersprachler gegenlesen." (IP6)

Moreover, one publisher with considerable expertise in developing evidence-based health information recommended that translations should be updated regularly to align with the most commonly spoken languages in the respective country. Additionally, it was noted that different language styles, such as American and British English, should be considered when planning translations.

Translations of subtitles and captions in videos

One publisher informed that CHI videos are generally produced in both German and English. The publisher placed the videos on YouTube, where subtitles and captions are automatically generated and offered in several additional languages. This is a functionality from YouTube that facilitated accessibility to videos. However, the translations were not verified by the publisher. The other publishers (n=5) could not share any experiences with this customization option

Other culture-sensitive customizations

At the time of the interviews, none of the interviewed publishers had implemented other culturally sensitive customizations than translations in additional languages.

One publisher explained that, despite internal discussions about the benefits of culturally sensitive CHI, it was decided not to culturally customize either the texts or images in the CHI.

This decision was justified by the aim to target people living in the respective country, even if the information is presented in a foreign language. The publisher emphasized the importance of familiarizing migrants with the terminology they can expect in medical care situations in that country. The use of standardized images and terms should make it easier for this target group to keep the information consistent and recognizable. However, limited resource capacity was also cited as another reason for not pursuing culturally sensitive customizations in CHI.

Another publisher stressed that culturally sensitive customizations would require comprehensive customizations of texts and images. For this publisher, cultural sensitivity also means that images and language in health information should address a broad audience. Therefore, the publisher adheres to a neutral design of the CHI. The publisher also added that in some cultures, the concepts of evidence-based medicine, informed decision-making and open communication about certain conditions are not established. In the publisher's view, these important principles should not be sacrificed for culturally sensitive customizations.

3.3.1.4.5. Points to consider in case of implementation

Selection of additional languages

It is recommended that health-related content or parts of the content be translated into additional languages that are commonly spoken in the target country. The selection of target languages should be based on current data on the linguistic distribution of the population. This includes both the number of people who speak a particular language as their mother tongue and the number of people who use this language as a second or third language [202, 209].

Language style

In order to avoid misunderstanding and to ensure that health messages are conveyed accurately and effectively, it is recommended to employ the most suitable linguistic style for translated CHI. Different variations in English, encompassing British, American, Canadian and Australian English, are characterized by disparities in, for example, spelling and grammar (IP).

Machine translation tools

The uncontrolled use of machine translation tools for the translation of CHI into additional languages without a professional human quality control is not recommended. The most common problems with machine translation programs are inappropriate terminology, lack of contextualization, grammatical confusion, misattribution of pronouns and unwarranted smoothing. While machine translation tools are useful for accurately translating individual words and phrases, it is not always able to accurately interpret the meaning of certain medical content [231-235]. In order to improve the quality of translated texts, it is recommended that the source texts are thoroughly prepared prior to translation. One potential solution is to pre-edit the source text, i.e. through simplifying the text by human experts. This approach requires more time, but is more cost-effective than post-editing and minimize the effort required for post-editing [236]. With regard to pre-editing, it is recommended to use short sentences, use lay terms or label medical vocabulary. The labelling of medical terms enables post-editors to more efficiently identify and rectify any issues with the machine translation, given that machine translations often lack standardized terminology [233].

Moreover, recent research shows that the quality of translation currently depends on the languages into which medical texts are translated. Brewster et al. (2024) demonstrated that ChatGPT 4.0 and Google Translate achieved translations of at least equivalent quality to those produced by professional translators from English into Spanish and Portuguese, with a low rate of clinically significant errors. These translations were evaluated on pediatric discharge instructions across measures of adequacy, fluency, meaning, and severity [237]. Additionally,

Rao et al. (2024) investigated the translation quality produced by ChatGPT 3.5 in comparison to Google Translate. The study focused on the translation of 132 sentences of patient instructions from English to Spanish, Russian and Vietnamese. The study revealed that in Spanish ChatGPT produced 3.8% translations errors, whereas Google Translate mistranslated 18.1% of sentences [238]. In contrast, there is an increased risk of clinically significant errors for languages spoken by a smaller global population with less widespread internet presence and various grammatical structures, syntax and vocabularies, e.g. Haitian Creole, Armenian or Lithuanian [237, 239, 240]. Furthermore, Rao et al. (2024) showed that in Russian, ChatGPT and Google Translate produced translation errors in 35.6% and 41.6% of all sentences, respectively. In Vietnamese, ChatGPT and Google Translate incorrectly translated 24.2% and 10.6% of sentences, respectively [238]. In conclusion, such languages require more training data for machine translation and, most importantly, additional human evaluation [237-240].

Moreover, a recent study evaluated the feasibility and utility of using professional human translators in comparison to Google Translate to translate patient education materials of radiation therapy written in plain language from English into Spanish, Portuguese, Punjabi, Simplified Chinese, and Vietnamese. The translations were evaluated anonymously from medical translators with regard to their grade level and readability. Spanish and Vietnamese pamphlets scored highest overall. However, human translators reached consistently better translations than Google Translate for all languages. However, Google Translate revealed acceptable translations in 90% of the domains tested [241].

Translations of CHI into additional languages for mobile devices

In the case of translating CHI into additional languages for smartphones, it is recommended to consider the length and presentation of text, as smartphones usually have smaller screens [211].

Labelling of translated CHI

The availability of multiple languages should be clearly labelled in CHI, making sure that all individuals with diverse linguistic backgrounds have equal access to relevant CHI. To signal a language change, certain icons are recommended for this purpose, while others are not advised (Table 21). In particular, the use of flag icons is not recommended to display different languages, as flags represent countries and not necessarily the language spoken in the country. For example, French is spoken in multiple countries (e.g. Switzerland, Canada,

Belgium), but the French flag only represents France. In contrast, the use of native language names and ISO codes are recommended for indicating language changes [242-245].

Table 21: Recommendations for labelling of translated CHI

Recommended icons for language labeling	**Example**
Drop-down menu with globe icon and translated and native language names	**Select your preferred language** **Deutsch ✓** English (Englisch) Español (Spanisch) Français (Französisch) Italiano (Italienisch)
Text link with translated and native language names	**IN YOUR LANGUAGE** **English** **Italiano** Italian **Ελλάδα** Greek **日本語** Japanese
ISO language codes (two-letter or three-letter)	**EN** **FR** **ES**
Not recommended icons for language labeling	**Example**
Flag icons [246]	

Culturally sensitive food lists

In order to avoid stereotypes or generalized recommendations, publishers of CHI are advised to consider including a diverse range of foods and alternatives with the aim to cover different individual preferences and health requirements of consumers [224].

Moreover, culturally sensitive food lists can be supplemented with traditional recipes from the target country and cooking-videos to enhance inclusion in the community and convey CHI vividly.

Furthermore, in order to increase the efficacy of dietary recommendations in a given cultural context, it is essential to remove unnecessary or less relevant information and to communicate

in a clear and action-oriented way. For example, the recommendation ‘Eat more beans’ can be more targeted than the general recommendation ‘Eat high-fibre foods’ [224].

Visual and linguistic design of culturally sensitive CHI

In the context of designing culturally sensitive CHI, it is essential to consider the diversity of society in an appropriate manner. It is recommended to illustrate people with a variety of ethnic backgrounds in terms of skin color, age, body shape and clothing. It is important that stereotypes and clichéd portrayals of individuals with a migration background are avoided. For instance, individuals with a migration background should not be portrayed exclusively in traditional country-specific clothing (e.g. all women wear a pencil skirt) or in a manner that evokes stereotypical external features. It is recommended that individuals with a migration background be represented in both patient and healthcare professional roles. It is also advised that socially disadvantaged and vulnerable target groups not be portrayed in an exaggeratedly stigmatizing manner. It is recommended that the design of CHI should be as neutral as possible, given that the target group is of a greater diversity. The diversity of society should be reflected in both text and images. The definition of certain groups in CHI can be particularly useful in the context of defining relevant differentiation criteria or when a specific target group is to be addressed in a certain context [210-212, 247-250]. For example, it may be considered beneficial to disseminate health information about sickle cell anemia especially to African or African-American individuals [251].

Furthermore, in the case of using names of illustrated characters in CHI it is recommended to use names that reflect the diversity of the population and to avoid religious names [210].

In addition, culturally sensitive CHI should be written in plain or, if necessary, in easy language. It is recommended to use a clear choice of words, a comprehensible and logical text structure. Additionally, a neutral and non-discriminatory language should be used to describe diversity-related characteristics such as sex, gender, sexual orientation, age, origin, migration history, religious affiliation, social status or disability. Stereotyping or discriminatory terms, such as “ageing society”, “ethnicity”, “foreign culture” or “foreigner”, should be avoided [211, 247].

Selection of appropriate media types

The results of a collaborative ethnographic field research from Geldermann et al. (2024) revealed that individuals with a migration background tend to prefer explanatory videos and infographics over straightforward text when seeking CHI. Overall, images and audiovisual

material are of significant importance in the utilization of CHI by individuals with a migration background. However, images without added informational value that serving only as abstract illustrations are unhelpful. Particularly helpful are explanatory graphics or videos that either completely replace a text or specifically supplement the text [211]. Culture-sensitive explanatory videos are particularly useful for people who are new immigrants and need support to find their way in a new country. Additionally, culturally sensitive explanatory videos can be used as a supportive tool in counselling settings or in language and integration courses [210-212].
In the case of developing explanatory videos, there are some points that should be taken into account: Explanatory videos should not exceed a length of five to a maximum of six minutes with a limited number of words. The narrative text in the video should be written in an easily understandable and gender-sensitive language, i.e. short sentence and simple phrases. It is recommended that explanatory videos are designed colorful, but not childish. Furthermore, the background music and volume as well as pauses should be chosen appropriate. It is also recommended to select a pleasant narrative voice [210].

The participatory creation of multilingual and culturally sensitive explanatory videos enables the inclusion of many different perspectives and can ensure cultural sensitivity, comprehensibility and relevance. The benefits of a participatory approach can be seen at many levels and have a positive impact on acceptance and satisfaction with the result, equal opportunities, quality and the ability to meet needs and requirements [252]. Throughout the participatory development process, it is important to continuously evaluate whether information is indispensable or too detailed. It is recommended that individuals with a migration background or counsellors for this target group, experts of CHI, stakeholders and sponsors are involved in the development process. Moreover, it is also essential to ensure that the contributors are adequately remunerated for their support. However, the participatory development process is a valuable approach for both culturally sensitive explanatory videos and other media types of CHI [210].

In the case of engaging an agency to create explanatory videos, it is important to ensure that the rights of use are unlimited in time, space and content. The videos should not contain any advertisements. Furthermore, flexibility and goodwill should also be considered in the number of feedback loops, as a participatory creation process may require a relatively high number of correction loops. In addition, it may be useful to acquire the raw video file for later changes and revisions of the video [210].

Review of culturally sensitive CHI

The participation of the target group is essential during the process of developing culturally sensitive CHI. This creates trust and guarantees that essential information is not lost, thereby saving time and resources. However, there is no universal method of customization that can be universally applied to a specific population or culture group [253]. Therefore, it is advisable to involve a diverse group of individuals to address a broad spectrum of the target population. There may be discrepancies in values and norms between individuals within a culture. Furthermore, people who are involved in the evaluation process should have appropriate linguistic and cultural expertized [211, 254].

3.3.2. Presentation customization options

The category presentation includes the customization options (1) presenting the same information in different visualizations, (2) presenting the same information in different levels of detail and (3) filtering and prioritizing the information.

As already mentioned, the customization options included in this category are not the primary focus of this thesis and are therefore examined only within a limited scope.

3.3.2.1. Same information presented in different visualizations

Visualization techniques have the potential to simplify complex data and present it in a user-friendly manner. The visualization of health data can help patients better understand their health status. Moreover, the benefits of data visualization are evident in their ability to improve decision-making processes, thereby leading to better patient safety and higher quality of care [255, 256]. In addition, effectively designed visualizations have been observed to bridge the gap between individuals with varying levels of health literacy [257]. However, the effectiveness of communication strategies in the healthcare sector depends on individuals' levels of health literacy, health numeracy (the capacity to understand and use numbers) and visualization literacy (the capacity to read and understand visualizations) [258].
Health data can be presented in a variety of formats, including running text, tables, diagrams, images or interactive visualizations. However, universal design preferences of users cannot be recommended [259]. To convey complex health information, the combination of static and interactive visualizations is recommended. While static visuals still remain dominant, interactive tools are becoming increasingly important due to their potential to boost user engagement and facilitate deeper data exploration. Choosing the right type of visualization - whether charts, maps, or dashboards - is essential to effectively address the target group's needs, the complexity of the data, and the intended objectives [255]. However, mobile devices frequently necessitate the utilization of simple and static visualizations due to their constrained screen dimensions (IP5).

To ensure visualizations achieve their full impact, it is advisable for publishers of CHI to assess their target group's level of understanding, e.g., by using the MINI-VLAT (Visual Literacy Assessment Test) questionnaire. This instrument provides an initial indication of a person's visualization literacy through a set of multiple-choice questions. These questions are designed to assess how well users can understand and interpret charts, infographics, and structured data presentations [260].

3.3.2.1.1. Special visualizations

Special visualizations are used to present information in a clear and coherent manner and to enable an interactive and personalized user interaction. Encouraging interactivity and creating a personalized user experience has been shown to make CHI more appealing, increasing users' willingness to engage with the content [256, 261, 262].

A range of special visualizations were identified in Phase 1 as part of the analysis of existing customization options, such as risk calculators, converter tools, educational features and interactive data visualizations.

Risk calculators

Risk calculators are essential tools to assess the individual's risk of a person to develop certain diseases or conditions. There exist many different calculators and they are used in various fields. For example, a diabetes risk calculator assesses the personal risk of developing diabetes in the next years, while a body mass index calculator is used to determine underweight, normal weight or overweight. A salt calculator helps to analyze the daily salt intake. An alcohol calorie calculator assesses the calorie content of alcoholic beverages and the physical activity required to burn off those calories [263]. In addition, pediatric medication dosage calculators can determine the optimal amount of active ingredient for children based on factors such as body weight, body surface area, age and recommended dosage for adults [264].

Converter tools

Converter tools facilitate the conversion of health data between different units of measurement, such as HbA1c values (converting HbA1c values between mmol/mol, mg/dl or % and vice versa), cholesterol levels (converting cholesterol values between mg/dl and mmol/L), body temperature (converting body temperature values between Celsius and Fahrenheit) or calories values (converting calorie values between kilocalories and joules).

Hovering effects

The hover or mouse-over effect is a visual change that is triggered when a user moves the mouse over an element without clicking on it. The representative sample encompassed transition effects (e.g., changing the opacity and background color of words or buttons), pop-out effects (e.g., resizing words, images, icons), hoverable drop-down menus or hovering words in a sentence (e.g., medical vocabulary, definitions).

Educational features

Educational features are designed to improve users' understanding of health topics by providing objective, clear and well-structured knowledge, skills and insights. Educational features can be implemented in various formats, including quizzes, gamification elements, or flashcards. Flashcards, for instance, are an interactive learning tool that present a question, term, or topic on one side and the corresponding answer, definition, or translation on the other side, facilitating active recall and reinforcing knowledge retention (Figure 17).

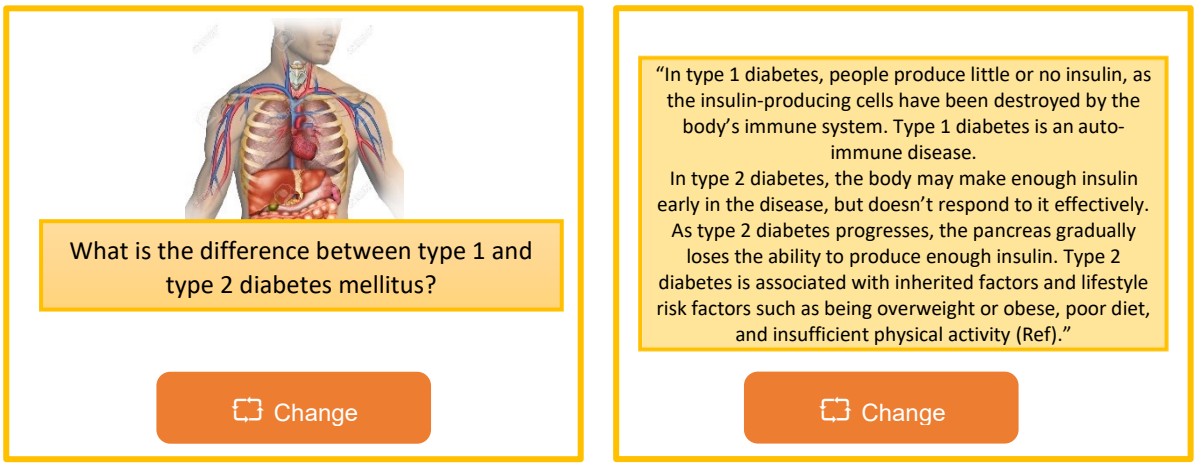


Figure 17: Flashcard as an educational feature

Interactive data visualizations

Interactive data visualizations enable users to interact with data in real time. This includes functions such as zooming and filtering of data, as well as changing the color, brightness, shape and motion of visual objects [265]. The representative sample of the analyzed CHIMs yielded interactive infographic about the insulin function via a 3D visualizations, interactive diagram and interactive map about epidemiological diabetes data, interactive storytelling's explaining the insulin and blood sugar metabolism and the differences of type 1 and type 2 diabetes mellitus.

3.3.2.1.2. Experiences of publishers of CHI

Most of the interviewed publishers (n=5) implement different visualizations for the same medical content. However, one publisher pointed out that an oversupply of different visualization types can be confusing and overwhelm users. The publisher therefore recommends offering users a maximum of two different visualization types per content or information:

> *„Also ich sehe keinen Sinn darin, die Informationen sowohl als Lauftext als auch als Tabelle als auch als Bild und als Video anzubieten. […] Ich würde ein, zwei Visualisierungen einsetzen, die die Leute am besten verstehen oder die die Mehrheit präferiert. Weil sonst wird man erschlagen mit einer Vielzahl an Optionen.“* (IP3)

Another publisher emphasized the importance of target group-specific and media-appropriate customization of visualizations. The publisher highlighted that visualizations should be adapted to the respective information channels, such as websites, YouTube, or social media platforms, as well as to specific target groups, such as young people or older adults. For example, placing short and concise graphics particularly on social media platforms.

Regarding the creation of various visualizations, the interviewed publishers reported several challenges. One publisher pointed out that the initial creation of different visualizations involves significant effort, as specific resources and often external support are required. However, with experience and routine production, this effort can be reduced. Another publisher pointed out the difficulty of selecting the appropriate type of visualization for each type of content. The visualization must not only be content-specific and tailored to the target group, but also convey the appropriate depth of knowledge. Furthermore, factors such as feasibility and the overall attractiveness of the information must be considered.

Some publishers stressed the relevance of graphics and videos in CHI. At the same time, they noted that creating these visualizations is challenging due to limited resources. In particular, the creation of explanatory videos was described as very time-consuming.

> *„Wir versuchen manche Texte mit Erklärvideos zu ergänzen, aber das ist ein sehr aufwendiger Prozess. Da braucht man eigentlich ein eigenes Kompetenzcenter, das solche Erklärvideos erstellt.“* (IP4)

Regarding the special visualizations, publishers considered hover effects as the most challenging special feature. Four of the six publishers reported that implementing hover effects presents both technical and content-related difficulties. Additionally, the implementation requires significant time and effort, as well as financial resources:

> *„Wenn ich eine Gesundheitsinformation habe mit 200 Fachbegriffen, sitze ich eine Woche da, um die alle zu definieren. Das ist ein wahnsinniger Aufwand. Es ist nicht nur dieser technische Aufwand, sondern man braucht auch Personen die alles definieren. Wir haben auch ein bisschen Probleme in der technischen Umsetzung, wir hatten uns auch ein bisschen mehr daraus gehofft. Das hört sich immer so leicht an.“* (IP6)

> *„Dieser Hover-Effekt ist umsetzungstechnisch laut unseren Programmierern nicht so einfach. Deshalb arbeiten wir mit Verlinkungen. Also wenn Fachbegriffe im Text sind, die man einfach braucht und die man erklären muss, dann wird auf ein Glossar einer externen Seite verlinkt.“* (IP1)

Furthermore, some publishers emphasized the importance of ensuring accessibility when implementing hover effects on websites. Hovering information poses a particular challenge for smartphones.

Few of the publishers had experience with the other special visualizations presented. It was shown in the interviews that most of the presented special visualizations are not implemented either because they are not yet widespread or because they cannot be implemented due to limited resources.

3.3.2.2. Same information presented in different levels of detail

Presenting health information at different levels of detail enhances its accessibility and comprehension for diverse target groups with varying cognitive abilities, language skills and literacy levels. Consumers of health information should be able to choose the information depth they require, from basic overviews of clinical conditions to comprehensive, more detailed information based on clinical trials, medical guidelines or recommendations from medical associations. For consumers desiring more in-depth information, specific details from relevant publications can be provided. These might include, for example, study characteristics, assessments of methodological quality, main outcomes, study limitations and author's conclusion.

In addition to assessing the consumer's visual literacy, it is also important to assess the consumer's text literacy, as people process information differently. For example, a consumer might easily comprehend complex written content but find visual representations confusing. Conversely, another individual may be skilled at interpreting graphs and charts, but may have difficulty processing lengthy text-based explanations [266, 267].

The FWF-funded A+CHIS project, in which this thesis is embedded, established two methods for analyzing consumer text and visual literacy. However, these analyses necessitate personal profile registration by consumers [268]:

(1) *Recording easy queries*: Examining consumers' search queries can help assess their level of understanding. If a consumer frequently looks up basic definitions or uses simplified language versions, this may indicate limited text literacy. In contrast, those who ask more nuanced or in-depth questions are likely to have stronger subject knowledge [268].

(2) *Interaction monitoring*: The way consumers interact with different types of content can also reflect their level of literacy. Consumers who consistently choose simplified materials or require repeated explanations may have lower text literacy. Similarly, those who avoid visual aids and prefer text-based explanations may struggle with visual literacy. Conversely, people who engage with complex visuals, such as interactive graphics or infographics, may have higher visual literacy, even if their text-based interactions suggest weaker reading comprehension [268].

3.3.2.2.1. Experiences of publishers of CHI

At the time of the interviews, five of the six publishers had already implemented the presentation of health information at varying levels of detail. Additionally, three publishers reported that the representation of general information alongside detailed information was positively rated based on user feedback. One publisher had no experience with this customization option.

Two of the six publishers expressed differing opinions on the benefit of providing consumers with detailed descriptions of relevant publications:

> *„Unsere Erfahrung zeigt, […], dass der breite Bedarf für diese Informationen so gering ist, dass wir diese Dokumentation der Studien und unserer Recherchen und Studienauswertungen nicht veröffentlichen, sondern nur intern halten. Einfach um an der Stelle die Aufwände zu sparen. Die Leserschaft dafür ist sehr speziell und sehr klein.“* (IP5)

> *„Für die Leute, die es genau wissen wollen, verlinken wir auf die anderen Informationstiefen. Dann kommt da der Methodenreport, dann kommen die Quellen. Das ist bei uns alles so zum Ausklappen gemacht, weil wir gedacht haben, das ist eine Information, die vielleicht nicht jeder braucht, nicht jeder lesen möchte, nicht jeder interessiert ist. […] Aber wir erstellen die Informationen für Nutzer*innen mit unterschiedlichem Bildungs- und Sprachniveau.“* (IP6)

Another publisher does not support providing the same information content in varying lengths (short, medium, long). This is based on the observation that individuals typically search for information using search engines, mostly through Google. According to the publisher, only about 2% of users directly look for specific information on a certain website. Users are offered various links via these search engines, whereby publishers have no control regarding which link the search engine displays to users. Therefore, there is a significant risk that the search engine will not direct link users to the appropriate version of the information. If multiple versions of the same information are offered, it could lead to confusion, as users may not find the version that suits them best. Consequently, the publisher has decided to provide only one version of the information to ensure clarity and consistency.

Another reported challenge is the increasing use of mobile devices for accessing health information online. This trend requires publishers of CHI to ensure that their websites are optimized for smaller screens like smartphones, where space for navigation and supplementary information is limited. Developers must design layouts that make key content easily accessible and legible, while maintaining usability across various device types.

Another publisher noted that users frequently use question-based queries in search engines. Adopting frequently asked questions (FAQ)-style headings for website content may enhance search engine visibility and improve engagement with the target audience.

3.3.2.3. Filtering and prioritizing of health information

The filtering and prioritizing of information enhance the process of information retrieval by tailoring information to individual needs and knowledge level, while avoiding irrelevant and redundant information. This mechanism should enable to filter information to various criteria such as age, gender, pre-existing conditions, current health status, treatment options or previous knowledge, as well as according to urgency or relevance (e.g., recent research results, only high-quality studies or recommendations from recognized medical associations).

User profile

One method to filter and prioritize information effectively is the creation of a personalized user profile. Such a profile allows users to specify individual characteristics, including demographic and psychosocial data, existing knowledge issues, health status, personal life style, personal risk factors, current treatments, and areas of interest. Based on this profile, irrelevant information can be algorithmically removed in a preliminary step. The patient's profile is then used to match relevant and irrelevant information. For instance, a patient diagnosed with T2DM may choose to filter information on specific complications or treatment options, whereas a patient without a pre-existing condition is more likely to receive general information on prevention and lifestyle modifications. Furthermore, certain medications that the user does not currently need (e.g., insulin), medications for which there is a known drug allergy, or gender-specific topics are removed if the user is of the opposite sex. After removing any irrelevant information, the remaining relevant information is ranked according to the user's needs and preferences. The irrelevant information will not be deleted, but is deprioritized and may still be accessible, for example in a table of contents or within expandable sections [269].

In-depth topics

Health information can be filtered by providing in-depth topics. These in-depth topics are customized by undertaking interactive tasks, such as exercises or knowledge tests. This ensures that consumers only receive information that is relevant to their individual situation, while deepening their knowledge (see Figure 18).

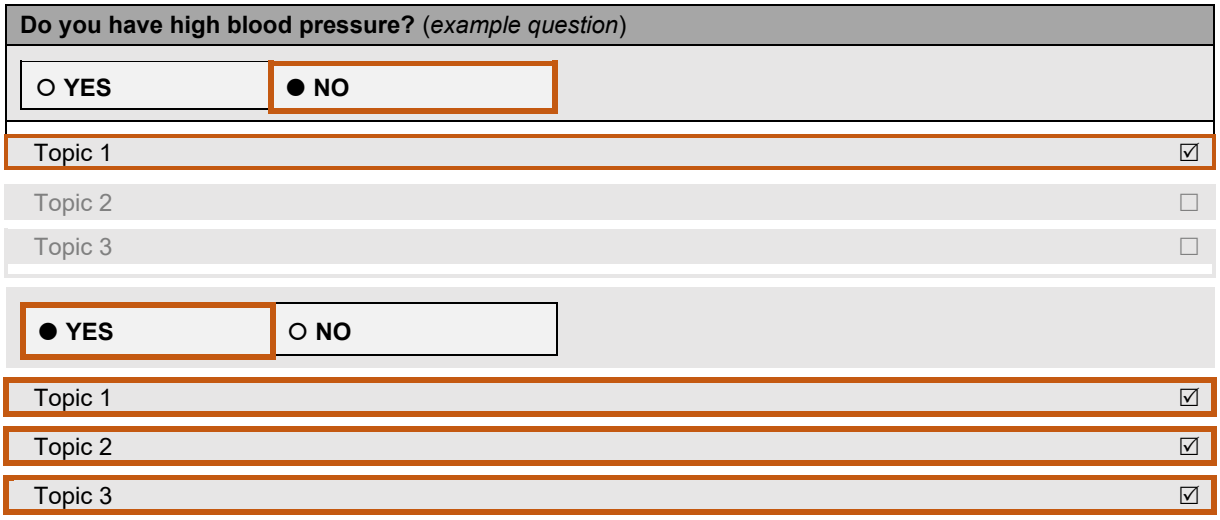


Figure 18: Example of in-depth topics

Some in-depth topics can be further subdivided into more detailed information. For example, in the case of T2DM, information about individual risk factors that can influence the development of diabetes-associated complications can be further filtered to gender-specific differences, such as sex and gender associations in smoking and diabetes (see Figure 19) or gender-specific differences of (adverse) effects of glucose-lowering and cardiovascular medications.

Higher risk for

Select Gender

- ○ Male
- ○ Female
- ○ Show both

Smoking is associated with the incidence of T2DM	♀ = ♂
Smoking prevalence differs between men and women in people with T2DM	♀ < ♂
Smoking increases diabetic macrovascular complications	♀ > ♂
Smoking increases diabetic microvascular complications	♀ = ♂
Smoking cessation decreases mortality and morbidity in people with diabetes mellitus	♀ = ♂
Smoking cessation is associated with weight gain in people with diabetes mellitus	♀ > ♂
Smoking cessation interventions are effective in people with diabetes mellitus	no gender specific data

Figure 19: Sex and gender associations in smoking and diabetes. Reproduced from Tramunt et al. [270] with permission of publisher Elsevier. The figure was published in an open-access article distributed under the terms of the Creative Commons CC BY license 4.0 (http://creativecommons.org/licenses/by/4.0/).

Info basket

A further approach to personalize health information would be to provide consumers with a so called ‘info basket’ where they can organize and rank information according to their individual interests. Consumers can collect and summarize all highly desirable and relevant information, including specific topics, illustrations, tables, videos, or glossary terms. The selected content can be modified within the info basket to change the order or remove information. Additionally, consumers should be able to download or print the selected information (Figure 20).

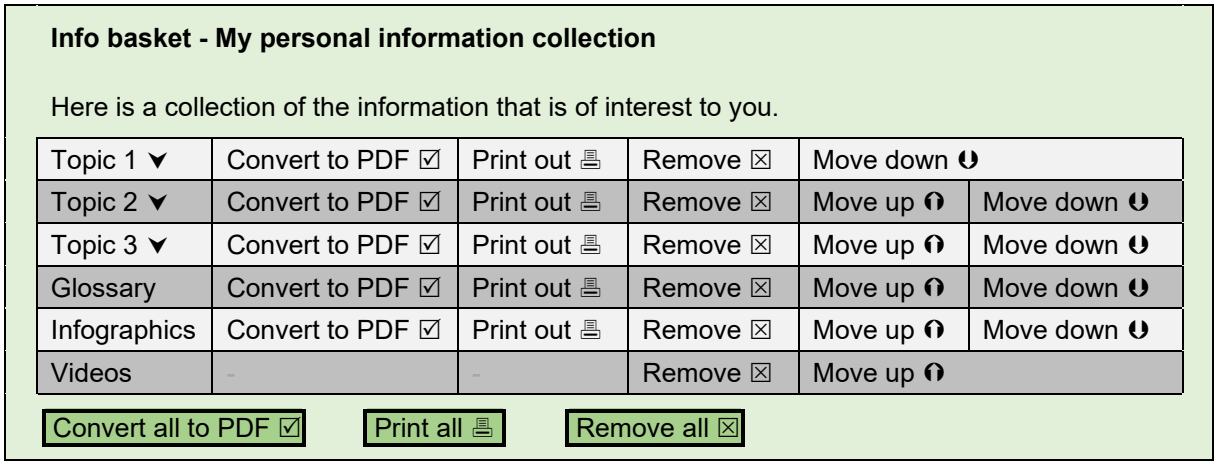


Figure 20: Info basket. Adopted from Stiftung Gesundheitswissen [271].

3.3.2.3.1. Experiences of publishers of CHI

The relevance of this customization option is perceived differently by the interviewed publishers. While two publishers stated that they do not offer this option to users, one publisher has fully implemented this customization option, and another has partially implemented it. Two publishers did not comment on this option.

One publisher emphasized that filtering and prioritizing information is only considered useful if users are given the opportunity to create a personal profile enabling to enter personal data. This allows users to customize and configure health information according to their individual needs. However, the expert considers a filtering function for standard information to be ineffective.

During the interviews, the publishers were presented with the filtering function for gender-specific differences as an example. Some publishers viewed this representation critically. One publisher pointed out that creating such an option is very resource-intensive. The main issue is that there is often a lack of high-quality data (e.g., studies with GRADE ratings) to reliably present gender-specific differences. Two publishers stressed the importance of considering and communicating gender-specific differences in health information when they are relevant. General differences, however, should be reported by default and not filtered. One publisher suggested that more detailed gender-specific differences could be filtered if necessary.

3.3.3. Web content accessibility customization options

The Web Content Accessibility Guidelines (WCAG) 2.2 provide a wide range of recommendations to design web content more accessible for people with different impairments, including blindness and low vision, deafness and hearing loss, limited movement, speech disabilities, photosensitivity, learning disabilities and cognitive impairments. The guideline addresses accessibility of web content on desktops, laptops, tablets, and mobile devices. The accessibility tools in the guideline based on four principles, that provide the foundation of the guideline: perceivable, operable, understandable, and robust. This guideline is the main guideline for web accessibility, developed by the World Wide Web Consortium (W3C) and updated in December 2024 [272]. At the time of writing the thesis, WCAG version 3.0 was under preparation. A working draft of this version was released in May 2024. This guideline applies to various types of web content including static, dynamic, interactive, and streaming content; visual and auditory media; virtual and augmented reality; and alternative access presentation and control. These guidelines also address related web tools such as user agents (browsers and assistive technologies), content management systems, authoring tools, and testing tools [273].

Beside the main guideline of web content accessibility, the W3C develops further guidelines for web accessibility, for example the Authoring Tool Accessibility Guidelines 2.0 (ATAG) and User Agent Accessibility Guidelines 2.0 (UAAG). Furthermore, supplemental guidance is available for enhancing accessibility for people with cognitive and learning disabilities [274], as well as specific accessibility requirements for users with disabilities in relation to audio and video [275]. For people with visual impairments, a working draft dated March 2016 is available [276].

The aim of this thesis was not to provide a detailed description of each accessibility tool. For detailed information on each accessibility tool and how to implement them, it is advised to refer to the relevant guideline [274].

4. Discussion

4.1. Answers to research questions

The main findings of the three research questions addressed in this thesis, are summarized and discussed in detail below.

Research Question 1: To what extent do existing CHIMs about T2DM across different media types enable consumers of CHI to individually select or pre-select content based on their specific situations and needs?

The analysis revealed that existing CHIMs predominantly use one-size-fits-all user interfaces, offering limited options for consumers to select or pre-select the preferred medical content, presentation forms, and levels of detail of information according to their individual situations and needs. The state-of-the-art analysis showed that existing CHIMs could theoretically provide a wide range of user-centered customization options. However, the implementation of the options identified in the representative sample was limited. None of the CHIMs analyzed – across websites, apps, print media, and videos – offered customization options in all theoretically feasible categories. Furthermore, the majority of CHIMs lacked user-centered customization features specifically related to medical content, such as tailoring treatment options, presenting benefits and harms of treatment options, or customizing information to individual health status or specific target groups. Instead, most CHIMs provided general customization options, such as linguistic, textual, or audiovisual customizations, which could equally implement in non-medical information materials. Only two websites offered options to tailor the level of detail (n=1) or to prioritize health information (n=2) based on users' personal needs [1].

Research Question 2: What similarities and differences exist between the identified user-centered customization options across different media types of CHIMs on T2DM?

The range of user-centered customization options differ considerably between the different media types of CHIMs on T2DM identified in the representative sample. Compared to p-HI, digital media were found to offer a higher degree of flexibility and customization. In the representative sample of CHIMs on T2DM, videos provided the most opportunities to consumers for customizations, whereas none of the p-HI offered any such options. However, the video customizations were limited to subtitle visualization and did not affect the informational content itself. The mean number of theoretically possible options across the main categories was low for both websites and apps. Overall, CHIMs more frequently included simpler customization features, such as language and text adjustments, than more complex ones, like personalized presentation format or medical content customization. This tendency may be due to the fact that the implementation of complex adaptations requires more advanced technological solutions, while the implementation of simpler adjustments is less challenging. Furthermore, the implementation may be less challenging as long as the content does not require modification [1].

Research Question 3: How should the content, design, and structure of a toolbox with user-centered customization options be developed to effectively support publishers of CHI in implementing these options in practice?

The expert interviews with publishers of CHI highlighted that a toolbox with a user-friendly interface and best practice examples of user-centered customization options will be more likely to be adopted and effectively used by publishers. A key requirement was that the toolbox be practical, intuitively understandable, and provide concrete support for implementing customization options. A clear structure and ease of use were emphasized as essential quality criteria.

The interviews experts also expressed the need to supplement theoretical explanations with illustrative examples to ensure that implementation recommendations are both comprehensible and applicable to their own practice. While the toolbox should avoid being overly theoretical, publishers valued the inclusion of evidence-based information on the effectiveness of individual customization options.

Overall, these expectations underscore the importance of bridging science and practice. The toolbox should combine evidence-based information with practice-oriented guidance to support the implementation of different customization options.

4.2. Presentation of novelty value and comparative explanations

This thesis addresses a highly topical and relevant issue in the intersection of health communication and health literacy, i.e. the necessity of customizing CHI to individual situations and needs. The importance of this topic has also been emphasized in other research.

Zapke et al. (2022) established a taxonomy of relevant personalization possibilities in CHI:
(1) Language: Customization of language style and cultural components, such as humor appeals or culturally sensitive language for non-native speakers.
(2) Sociodemographic factors: Customization of medical content related to gender-specific information. Men and women differ in their health-related aims, motivators and social role expectations. While women tend to seek emotional support, men favor fact-based health knowledge. Men react more strongly to challenges and competitive aspects, while women prioritize health aspects more strongly. Furthermore, biological differences, such as genetic, hormonal and risk-related factors (e.g. prediabetes) require gender-specific adjustments.
(3) Individual living environments: The acquisition of health literacy depends not only on individual learning, but is also influenced by external factors, such as professional and leisure activities. The concept of context matching, which involves adapting the CHI to the context of life, has been demonstrated to promote behavioral changes.
(4) Type of presentation: Multimodal representations, such as videos, images, pictograms or texts, have been shown to reduce cognitive load and improve information processing by appealing to multiple sensory systems. Audiovisual content has also been demonstrated to increase satisfaction and support decision-making. Older adults, who often have a lower cognitive capacity, benefit particularly from multimodal information. Similarly, people with low cognitive and reading ability require simplified and visually supported presentations.
(5) Gain- und Loss-Framing: Gain framing, which emphasizes positive consequences, is particularly suitable for motivating health-promoting behavior, for example in the context of disease prevention. Conversely, loss framing, which emphasizes negative consequences, is more effective in the early detection of diseases and the avoidance of unhealthy behavior. Messages that are framed in a negative way, for example in the context of diabetes prevention, have been shown to strengthen attitudes and perceived control. The perception of gain-framed CHI is also influenced by gender and individual risk [105].

Ma et al. (2005) developed an adaptive profile-controlled web portal for the management of diabetes. The web portal has been designed to provide diabetes patients with customized information to help them better understand and manage their disease. The web portal

dynamically adapts the content provided to the user's profile including factors such as age, stage of diabetes, level of knowledge and personal preferences. The initial step is to filter relevant and non-relevant information. For example, information about insulin is removed if the patient does not inject insulin. Information is then prioritized. Significant information is prioritized first, such as factors that have a negative impact on health status (e.g. excessive alcohol consumption, smoking, high-fat diet) or urgent therapeutic measures that are required (e.g., hypoglycaemia or high ketone levels). The subsequent presentation of information is dependent upon the user's level of knowledge, with basic and necessary information being presented first for people who have been diagnosed with diabetes. This is followed by further information necessary for self-management and finally information on diabetes complications. In addition, users have the capacity to organize information in the web portal according to personal relevance and importance. In this web portal, the patient's electronic medical record and medical history are used to generate the patient profile. Patients are prompted to complete computerized medical forms or to record the information themselves, with the option of review by healthcare providers [269].

Zapke et al. (2022) investigated the question of how digital CHI for the prevention of T2DM can be personalized and communicated in a needs-based manner. To this end, the authors of the study identify different approaches to personalize and systematize them in a taxonomy. Three promising approaches were individually designed and tested using a chatbot-based demonstrator as part of quantitative online studies. The results obtained from these studies indicate that textual representations are preferred over audiovisual content, and that the utilization of 'gain frames' (positive framing) is perceived as more beneficial than 'loss frames' (negative framing) when communicating risk factors. No statistically significant difference was observed between gender-sensitive and gender-neutral health information with respect to subjective content perception, usefulness, and the intention to engage in health-promoting behavior [105].

Nguyen et al. (2022) investigated the effectiveness of different strategies for adapting the presentation of digital CHI. A comparison was made between user-driven adaptation (customization), in which users choose the form of presentation autonomously, and system-driven adaptation (personalization), in which the system specifies the form of presentation based on individual characteristics. An online experiment with 490 participants examined the effects on factors such as attention, perceived relevance, satisfaction with the website and information retrieval. The results show that both customization and personalization are more

effective than no customization, although the effectiveness varies depending on variables such as health literacy and user age. The authors conclude that when designing digital CHI, a strategic decision should be made about whether to offer a personalized presentation or the option of customization [277].

The described studies focused primarily on approaches to customization regarding content and presentation forms (e.g., visual vs. text-based information). A systematic analysis of consumers' language preferences is only described to a limited extent, underlining the necessity for detailed research into consumers' language needs and preferences.

The results of this thesis deepen current research by emphasizing the importance of tailoring language to specific target groups. They align with a key recommendation of the guideline on evidence-based health information, recommending consideration of linguistic and cultural requirements for a respectful and effective health communication [110].

This thesis represents a novel contribution to the fields of health communication and health literacy by developing a toolbox that supports publishers of CHI in tailoring health information to consumers' individual needs and preferences through user-centered customization options. The development of the toolbox PHOCUS was based on a systematic search and analysis of currently available customization options across different media types, and was refined by practical insights gathered from CHI publishers regarding implementation challenges. PHOCUS is characterized by a practical orientation, combining scientific evidence with llustrative examples and practical recommendations to facilitate the effective implementation of user-centered customization options. PHOCUS offers several benefits:

- **Time saving**: Publishers of CHI receive direct access to a compendium of user-centered customization options and key considerations in case of its implementation, thereby reducing the need for independent and time-consuming research.
- **Combination of theory and practice**: The toolbox incorporates scientific findings about the efficacy of customization options, supplemented by several practical examples, aiming to facilitate the implementation of customization options and increase the acceptance of the toolbox.
- **Focus on language customization options**: The detailed examination of linguistic needs enhances an accessible health communication, especially for target groups with linguistic barriers.

4.3. Critical reflection on the content and methods

The representative sample for the state-of-the-art analysis was relatively small, as only 114 CHIMs were analyzed, i.e. 19 materials per media type (website of diabetes organization, websites of other organizations, p-HI of diabetes organization, p-HI of other organizations, apps, videos). However, it should be acknowledged that a priori defined criteria to end data analysis was used and data saturation was reached based on these criteria. A further limitation was that the analysis referred only to CHIMs on T2DM; CHIMs on other medical topics or diseases were excluded, but could have reveal additional customization options. In addition, the search for CHIMs was restricted to language (only CHIMs published in German and English were included) and publication country (only CHIMs of countries with low mortality rates were included). These limitations may limit the generalizability of the findings. Furthermore, the search for relevant CHI videos was restricted to YouTube and did not consider alternative streaming media platforms. Moreover, the search for CHIMs excluded disease-related assistive technologies and tools to facilitate disease (self)-management. This consciously exclusion could have limited the range of user-centered customization options, as such technologies and tools often provide specific customizations, that are relevant for certain target groups [1]. A further limitation was that the extended analysis only included websites. Conducting an analogous analysis in apps might have revealed additional and expanding the range of user-centered customization options.

Some further methodological limitations have to be considered when interpreting the results of the internal workshop, which relate in particular to the selection of the participants and moderation of the workshop. Firstly, the participants of the workshop consisted of people with academic expertise. This led to missing perspectives on relevant customization options from direct end-users of CHI, e.g., patient representatives. Secondly, as the author of this thesis conceptualized and moderated the workshop itself, unconscious biases may have influenced the course and outcomes of the workshop. An external and neutral moderation of the workshop could potentially have achieved greater objectivity and less influence from researcher interests.

A major methodological limitation of this thesis derived from the small sample size of the expert interviews, with only six interviews conducted in total. In addition, the interviews were only conducted with publishers from Germany and Austria. This may have led to an underrepresentation of other relevant user-centered customization options and specific experiences and challenges during the implementation process. In particular, country-specific contexts especially outside the German-speaking region are not presented. In addition, the

transcribed interview results were not externally validated for consistency and transparency by an independent second researcher. This may have reduced the reliability of the results. Furthermore, the final categories and interpretations were not presented to the interview partners for feedback. This step of participant validation was not undertaken.

Another limitation was that the supplementary PubMed searches conducted in Phase 3, intended to refine practical implementation aspects of the toolbox, were focused and non-systematic. These searches were not designed as formal systematic or scoping reviews; rather, they served to quickly identify recent and relevant literature on key considerations for implementation of specific customization options. Thus, no detailed reporting of search strategies (e.g., search strings, eligibility criteria, or screening procedures) was provided. This limits the transparency and reproducibility of the literature identification process for this phase.

Another limitation of this thesis was the need to prioritize within the dissertation project. It was not possible to completely implement all the desired expectations for the final toolbox requested by the interviewed publishers of CHI. In particular, the systematic exploration of target group-specific information for individual customization options could not be realized within the scope of this project. In addition, evidence-based syntheses on the effectiveness of individual customization options was not systematically explored. Finally, the category of presentation customization options could not be systematically explored in an analogous way as the category of language customization options, with incorporating more different illustrative examples and key considerations for implementation.
The toolbox was primarily conceptualized as a descriptive and exploratory framework, intended to systematically map and categorize existing user-centered customization options found in available health information materials. It was not within the scope of the dissertation project to design and to evaluate outcomes or user impact empirically, and therefore the potential benefits listed are based on theoretical considerations and expert insights. Thus, the recommendations in this phase must be considered eminence-based rather than evidence-based.

Finally, the newly developed toolbox PHOCUS could be particularly helpful for publishers of CHI with limited experience in producing personalized health information. However, for publishers with extensive expertise and established quality standards, the added value is likely to be limited.

4.4. Implications for theory and practice

A key implication of this thesis is that publishers of CHI have recognized the relevance of tailoring health information to individual needs and circumstances, and acknowledge that preferences vary across target groups. This was particularly reflected in the expressed need from all interview partners for evidence-based information on personalization preferences for specific target groups of CHI (e.g., adolescents, older adults, people with disabilities), underscoring the diversity of information needs and preferences.

Furthermore, the expert interviews also revealed a partial discrepancy between general awareness and specific knowledge regarding individual customization options. A significant discrepancy was identified in the knowledge of individual customization options between small and large publishing organizations. For example, some publishers were unaware of the difference between plain and easy language and their specific rules. The interviews indicate that knowledge gaps regarding specific customization options may be more pronounced in smaller organizations than in larger ones. However, due to the small sample size, no statistically significant conclusions can be drawn about differences related to organizational size. Further research with a larger and more diverse sample is needed to explore and justify this hypothesis.

Furthermore, at the time of conducting the interviews, none of the publishers had implemented culturally sensitive CHI beyond translating medical content into additional languages.

The successful implementation of customizable CHI is predicated on a comprehensive understanding of the needs and preferences of specific target groups. However, the expert interviews indicated that professional expertise alone is insufficient for achieving effective personalized health communication. The creation of accessible and individually tailored health information is a resource-intensive process that necessitates strategic decisions at the organizational level. In addition to professional expertise, supplementary technical and financial resources are frequently required, yet not all publishing entities possess these prerequisites. To illustrate, AI-based technologies can significantly assist the translation of complex medical content into lay language. Nevertheless, a quality control by human experts remains still necessary to ensure both linguistic simplification and factual accuracy.

Furthermore, the implementation of certain customization options require collaboration with external professionals, such as multimedia producers, sign language interpreters, and representatives of the target groups themselves. However, such collaborations are not always available or financially viable for all publishers.

In summary, the results of this thesis imply that professional expertise and organizational capacities are crucial mediators between awareness und realistic implementation of user-centered customization options. The availability of resources was identified as a key factor in the successful implementation process.

4.5. Outlook and suggestions for further work

This thesis proposes several suggestions for further research.

The author of this thesis recommends that future efforts should focus on transferring knowledge and developing skills related to customizing CHI. For example, this could be achieved through workshops or training programs. The expert interviews highlight a broader need for training and capacity-building across all types of organizations. Importantly, such training should not focus on technical implementation aspects, but also on helping CHI developers navigate the uncertainty that often accompany early-stage decisions around customizations. Furthermore, developers of CHI should be trained in the understanding of diverse user needs. Developers need to appreciate the wide range of constantly changing cognitive, linguistic, and cultural differences of user target groups and the related challenges of specific customization options as well as uncertainty in how best to design customization options that will work effectively for the diverse user groups.Furthermore, the implementation of customization options in CHI could be strengthened by incorporating evidence-based recommendations on specific personalization strategies into existing guidelines or quality standards for health information, e.g., in the guideline for evidence-based health information [110]. Such recommendations would provide concrete, practice-oriented guidance for information providers, support the standardization of customization processes, reduce uncertainty in implementation, and ultimately contribute to maintaining and improving the quality of an effective health communication.

Moreover, there remains a considerable need for research to systematically identify target group-specific information needs and preferences, and to better incorporate these into CHI. Further studies are necessary to determine the most appropriate customization options for specific target groups and media channels, as well as to gain a deeper understanding of target groups' media channel preferences. However, it is also important to acknowledge that the information needs and preferences of target groups are dynamic and may change over time due to evolving health literacy, digital habits, or sociocultural shifts. Therefore, regular

reassessment and updates of these needs should be an integral part of CHI development and research.

In this context, it is important to note that the toolbox PHOCUS shows certain limitations in addressing the full spectrum of potential target groups. For example, specific information needs of children and adolescents were not explicitly considered. It is therefore recommended that future work efforts and subsequent toolbox refinements expand the scope to include additional target groups, in order to enhance both the usability and inclusivity.

Some experts raised concerns that an excessive provision of visualizations in CHI may overwhelm consumers. This points to a critical need for further research on the optimal number and design of visual elements in CHI. Specifically, future studies should explore how many visualizations are most effective to support comprehension and information retention, while avoiding cognitive overload. Additionally, there is a notable research gap concerning how CHI can be visualized in a way that adequately addresses the cultural, cognitive, and linguistic needs of diverse target groups. Understanding these dimensions is essential to ensure that visual representations are inclusive, accessible, and truly supportive of informed health-related decision-making across different populations.

Furthermore, it is imperative to systematically evaluate the effectiveness of individual user-centered customization options. This can be achieved through randomized controlled trials and structured user feedback to assess the impact, acceptance, and comprehensibility of such customizations within CHI. Incorporating user feedback into a continuous, iterative development process is essential to ensure that accessible CHI is not only available, but also actively used by the intended target groups. Accordingly, it is recommended that future research addresses these gaps in order to further optimize the toolbox and enhance its practical applicability.

Moreover, it is recommended to conduct additional interviews, particularly with publishers of CHI outside German-speaking countries, in order to broaden the understanding of international practices and challenges. In addition, it would be advisable to consult experts who have specific experience in developing culturally sensitive health information. Their insights could offer valuable contributions to the refinement of existing recommendations and the development of practical implementation strategies.

Further research is also needed to assess the effectiveness of AI-technologies in translating CHI into easy language. Although several projects are currently ongoing in this domain, they remain incomplete, and no final publication was available at the time of writing this thesis. To date, only a single study has been conducted in which an AI tool was used to simplify citizen-oriented content into easy language. The topics covered by the tool included reporting lost and found items, applying for parental leave, and obtaining a police clearance certificate [278]. However, as a first follow-up research project stemming from the dissertation, the doctoral candidate together with a research team, is conducting a scoping review to map the existing evidence on automated approaches for simplifying complex medical texts into layperson-friendly language. The protocol for this scoping review was registered on OSF in May 2025 [279].

Moreover, this thesis also points the need for closer collaboration across linguistics, education, psychology, sociology, technical and health sciences disciplines to ensure that user-centered customizations in CHI are both effective and contextually appropriate.

In the future, the dissemination of CHI will increasingly rely on subject-specific and personalized digital formats. Real-time customization, already common on social media platforms, will play a growing role in health communication. Moreover, it will no longer be necessary for websites to offer all possible information on a given topic. Instead, the emphasis will shift toward delivering highly targeted, user-specific content that aligns with individual preferences, abilities, and contexts. AI will be central to this transformation, enabling the creation and presentation of customized health information in real time. For example, AI-driven systems may detect user characteristics, such as gender, health literacy, or neurodiversity, and automatically adapt the format and complexity of content accordingly. For example, customizing textual information to visual summaries for male users or simplifying design and text for individuals with attention-deficit/hyperactivity disorder [280].

To support and shape this paradigm shift, it is essential to pilot the toolbox PHOCUS in future research. This will allow for an assessment of its practical applicability, highlight areas for optimization, and support its integration into long-term strategies for high-quality, user-centered CHI.
Anyway, the toolbox of user-centered customization options developed in this thesis should be understood as a dynamic instrument that requires continuous evaluation and refinement. Regular updates based on new research findings and changing information needs of target

groups are essential to maintain its relevance and practical utility. Where appropriate, newly identified customization possibilities should be integrated into the toolbox to ensure it remains a comprehensive and up-to-date instrument.

5. Conclusion

The development of the toolbox PHOCUS is a foundational step in providing publishers of CHI with a structured, conceptual resource to support the development of customized health information. The toolbox offers a comprehensive overview, based on the findings of this research, of how medical content can be customized to individual needs and preferences.

PHOCUS provides a theoretical and conceptual framework based on the hypothesis that user-centered customization options may lead to improved understanding, relevance, and ultimately, effectiveness of CHI. However, this hypothesis requires rigorous empirical validation. Therefore, a crucial next step is to systematically test the effectiveness of the proposed customization options through further research. Such studies could significantly contribute to the broader goal of strengthening health literacy.

To ensure its long-term relevance and potential, the PHOCUS toolbox must also be continuously expanded, updated, and co-developed through active collaborations between health science, practice, and specific target groups of CHI. The ultimate goal of this iterative process is to bridge the gap between theory and practice, fostering the development of CHI that is not only theoretically grounded but also demonstrably effective.

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Appendix

Appendix 1 – Search strategy PubMed

Date of search: 22.07.2021

Search	Details	Results
#1	Search: **Diabetes Mellitus, Type 2[MeSH Terms]**	144,182
#2	Search: **noninsulin?depend*[Text Word] OR non insulin?depend*[Text Word]**	12,421
#3	Search: **diabet* mellitus[Text Word] OR type 2 diabet*[Text Word]**	495,494
#4	Search: **T2D?[Text Word] OR NIDDM[Text Word]**	19,067
#5	Search: **#1 or #2 or #3 or #4** [=Diabetes Mellitus Type 2]	496,578
#6	Search: **Consumer Health Information[MeSH Terms]**	10,935
#7	Search: **Decision Making[MeSH Terms]**	213,242
#8	Search: **Decision Making, Shared[MesH Terms]**	1,034
#9	Search: **Pamphlets[MeSH Terms]**	3,999
#10	Search: **broadside as topic[MeSH Terms]**	36
#11	Search: **posters as topic[MeSH Terms]**	237
#12	Search: **Health Communication[MeSH Terms]**	2,801
#13	Search: **Health Information Systems[MeSH Terms]**	1,431
#14	Search: **Decision Support Systems, Clinical[MeSH Terms] OR Decision Support Systems, Management[MeSH Terms]**	9,490
#15	Search: **mobile applications[MeSH Terms]**	8,196
#16	Search: **smartphone[MeSH Terms]**	6,255
#17	Search: **blogging[MeSH Terms]**	1,030
#18	Search: **digital therap*[Text Word] OR digital tool*[Text Word] OR digital medicine[Text Word] OR mobile application*[Text Word] OR app[Text Word] OR apps[Text Word] OR smartphone[Text Word] OR blogging[Text Word] OR video*[Text Word] OR streaming media[Text Word] OR YouTube[Text Word]**	237,434
#19	Search: **consumer information[Text Word] OR consumer health information[Text Word] OR health information[Text Word] OR health communication[Text Word] OR patient information[Text Word] OR medical information[Text Word] OR written information[Text Word] OR tailored information[Text Word]**	54,846
#20	Search: **decision making[Text Word] OR decision aid*[Text Word] OR decision tool*[Text Word] OR decision guide*[Text Word] OR decision support*[Text Word]**	266,693
#21	Search: **broadside*[Text Word] OR poster*[Text Word] OR pamphlet*[Text Word] OR brochure*[Text Word] OR leaflet*[Text Word] OR flyer*[Text Word] OR folder*[Text Word] OR booklet*[Text Word]**	376,226
#22	Search: **#6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21** [=Consumer Health Information Systems]	1,021,520
#23	Search: **#5 and #22**	10,313
#24	Search: **#5 and #22** Filters: **in the last 5 years**	4,291
#25	Search: **#5 and #22** Filters: **Review, in the last 5 years**	527
#26	Search: **#5 and #22 Filters: Systematic Review, Review, in the last 5 years**	632
#27	Search: **#5 and #22** Filters: **Meta-Analysis, Systematic Review, Review, in the last 5 years**	643
#28	Search: **#5 and #22** Filters: **Patient Education Handout, Meta-Analysis, Systematic Review, Review, in the last 5 years**	643

Appendix 2 - Interview guide

Das qualitative Leitfadengespräch orientiert sich an drei Themenbereiche:

Themen	Frage(n) bzw. Ergänzungsfrage(n)
Thema 1: Erfahrungen mit der Implementierung von Adaptionsmöglichkeiten zum Thema X **(nach jeder Kategorie)**	**1. Welche Erfahrungen haben Sie mit den soeben vorgestellten Adaptionsmöglichkeiten?** a. Welche Adaptionsmöglichkeiten sind gut implementierbar? Warum/Beispiel? b. Bei welchen Adaptionsmöglichkeiten gibt es Herausforderungen? Warum/Beispiel? c. Welche Adaptionsmöglichkeiten haben Sie noch nie eingesetzt? Warum nicht? d. Welche Adaptionsmöglichkeiten werden für bestimmte Zielgruppen bevorzugt? Warum/Beispiel? e. Welche Adaptionsmöglichkeiten werden für bestimmte Formate von Gesundheitsinformationen bevorzugt? Warum/Beispiel?
Thema 2: Weitere Adaptionsmöglichkeiten **(nach jeder Kategorie)**	**2. Kommen Ihnen weitere Adaptionsmöglichkeiten in den Sinn, die hier noch nicht aufscheinen?** a. Wenn ja: Welche? Gleiche Unterfragen wie bei Thema 1
Thema 3: Erwartungen an die Toolbox	**3. Welche Informationen zu Adaptionsmöglichkeiten sollte eine Toolbox enthalten, damit sie für Sie als Ersteller*in bzw. Herausgeber*in von Gesundheitsinformationen hilfreich ist?** a. Warum genau diese Informationen? b. Wie ausführlich/detailliert sollte so eine Toolbox sein? c. Welche Informationen wären für Sie weniger relevant?

Gibt es noch etwas, dass Sie gerne hinzufügen möchten?

Vielen Dank für das Gespräch!

Appendix 3 - Votum Ethics Committee

Medizinische Universität Graz
Ethikkommission

Neue Stiftingtalstr. 6 - West, Q/04, A-8010 Graz
ethikkommission@medunigraz.at
Tel.: +43 / 316 / 385-71400

VOTUM

gültig bis 22.08.2025

EK-Nummer:	36-358 ex 23/24
Studientitel:	Nutzerzentrierte Adaptionsmöglichkeiten in Gesundheitsinformationen
Prüfer:	Prof. Dr. Andrea Siebenhofer-Kroitzsch Institut für Allgemeinmedizin und evidenzbasierte Versorgungsforschung
Sponsor:	Institut für Allgemeinmedizin und evidenzbasierte Versorgungsforschung
Ansprechpartner:	Prof. Dr. Andrea Siebenhofer-Kroitzsch, 8010 Graz, Neue Stiftingtalstraße 6 - WEST
CRO:	-
Ansprechpartner:	
Antragsteller:	Med.Uni Graz
Ansprechpartner:	BSc, MSc Cornelia Krenn

Die o.a. Studie wurde von der Ethikkommission erstmals im 'expedited Review' am 08.05.2024 behandelt. Die Ethikkommission ist zu folgendem Schluss gekommen:

Es besteht kein Einwand gegen die Durchführung der Studie in der vorliegenden Form.

Kommissionsmitglieder, die für diesen Tagesordnungspunkt als befangen anzusehen waren und daher gemäß Geschäftsordnung an der Entscheidungsfindung und Abstimmung nicht teilgenommen haben: keine

Zur Beurteilung vorliegende Dokumente:

Dokumente eingegangen am 09.04.2024, begutachtet im 'expedited Review' am 08.05.2024	
✓ Cover Letter	09.04.2024
✓ Antragsformular signiert	09.04.2024
✓ Originalprotokoll 1.0	09.04.2024
✓ Informed Consent Form 1.0	08.04.2024
✓ Sonstiges: Interviewleitfaden 1.0	09.04.2024
Dokumente eingegangen am 27.05.2024 (in der nächsten Begutachtung mitbegutachtet)	
✓ Antragsformular signiert	14.05.2024
✓ Sonstiges: E-Mail Stellungnahme zur Bearbeitungsmitteilung	27.05.2024
Dokumente eingegangen am 31.07.2024, begutachtet im 'expedited Review' am 22.08.2024	
✓ Letter of Authorization Med.Uni Graz, ohne Auflage	30.07.2024

Die Ethikkommission geht - rechtlich unverbindlich - davon aus, dass es sich um keine klinische Prüfung nach AMG bzw. MPG handelt.

Es handelt sich um eine Studie im Rahmen einer Dissertation.

Das Votum der Ethikkommission berührt in keiner Weise die alleinige Verantwortung der Prüferin / des Prüfers / der Prüfer für die ordnungsgemäße Durchführung der Studie unter Einhaltung aller einschlägiger gesetzlicher Bestimmungen und Richtlinien.

Weiters machen wir darauf aufmerksam, dass der Kommission unverzüglich zu melden sind:

Medizinische Universität Graz, Neue Stiftingtalstraße 6, A-8010 Graz. www.medunigraz.at
Rechtsform: Juristische Person öffentlichen Rechts gem. UG 2002, Information: Mitteilungsblatt der Universität. UID: ATU 575 111 79. Bankverbindung: Raiffeisen Landesbank Steiermark IBAN: AT443800000000048510, BIC: RZSTAT2G

- Abweichungen vom Protokoll aus Sicherheitsgründen oder Protokolländerungen

- Änderungen, die das Risiko der Teilnehmer/-innen erhöhen oder die Durchführung der Studie wesentlich beeinflussen

- Mutmaßliche unerwartete schwerwiegende Nebenwirkungen - SUSARs (AMG-Studien ab 1.5.2004; Directive 2001/20 EC), SADEs (Verordnung 74/2017 und 746/2107) oder schwerwiegende unerwünschte Ereignisse - SAEs (andere Studien)

- Jegliche Information über sonstige Umstände, die die Sicherheit der Teilnehmer/-innen oder die Durchführung der Studie beeinträchtigen können

Dieses Votum gilt für ein Jahr ab dem Datum der Ausstellung. Bei längerer Studiendauer ist rechtzeitig vor Ablauf der Gültigkeit des Votums ein Zwischenbericht vorzulegen (Berichtsformular), um eine etwaige Verlängerung zu erlangen.

Graz, 22. August 2024

Univ.Prof.Dr.Hans Peter Dimai
Vorsitzender

Univ.Prof.Dr.Thomas Griesbacher
Stv. Vorsitzender

Achtung: Bitte bei allen das Projekt betreffende Schreiben oder telefonischen Anfragen die EK-Nummer angeben!

Medizinische Universität Graz, Neue Stiftingtalstraße 6, A-8010 Graz, www.medunigraz.at
Rechtsform: Juristische Person öffentlichen Rechts gem. UG 2002. Information: Mitteilungsblatt der Universität. UID: ATU 575 111 79. Bankverbindung: Raiffeisen Landesbank Steiermark IBAN: AT443800000000049510, BIC: RZSTAT2G

Appendix 4 - Data protection and consent declaration of qualitative guideline interview

Med Uni Graz *Pioneering Minds*

Institut für Allgemeinmedizin und evidenzbasierte Versorgungsforschung

Schriftliche Datenschutz- und Einwilligungserklärung
Dissertationsprojekt: „Nutzerzentrierte Adaptionsmöglichkeiten in Gesundheitsinformationen“

Sehr geehrter Teilnehmer, sehr geehrte Teilnehmerin!

Ich lade Sie ein, im Rahmen des oben genannten Dissertationsprojektes an einem qualitativen Leitfadengespräch teilzunehmen.

1. **Was ist ein qualitatives Leitfadengespräch?**

In diesem qualitativen Leitfadengespräch werden vorbereitete Fragen von einer Doktorandin anhand eines Leitfadens an Sie gestellt. Es findet somit eine thematische Eingrenzung statt. Die interviewende Person hat hierbei die Aufgabe Ihrer Erzählung zu folgen. Das Interview dient dazu, neue Anregungen und Sichtweisen zu einem bestimmten Thema von den Teilnehmerinnen und Teilnehmern zu bekommen.

2. **Was ist der Zweck des Leitfadengesprächs?**

Das Ziel des Dissertationsprojektes ist die Entwicklung einer Toolbox mit nutzerzentrierten Adaptionsmöglichkeiten in Gesundheitsinformationen. Diese Toolbox soll Herausgeber*innen von Gesundheitsinformationen einen umfassenden Überblick über verschiedene Adaptionsmöglichkeiten von Inhalten bieten, die den Nutzer*innen je nach ihren Präferenzen zur Auswahl angeboten werden können. Dafür werden qualitative Leitfadengespräche mit Herausgeber*innen von Gesundheitsinformationen geführt. Die daraus gewonnenen Erkenntnisse tragen dazu bei, die Toolbox um Erfahrungen mit einzelnen Adaptionsmöglichkeiten zu ergänzen und Erwartungen von Herausgeber*innen von Gesundheitsinformationen an eine solche Toolbox zu erfahren sowie weitere potenzielle Adaptionsmöglichkeiten zu identifizieren.

Diese Studie hat von der zuständigen Ethikkommission eine positive Stellungnahme erhalten.

3. **Ablauf**

Das Leitfadengespräch wird aufgezeichnet und kann entweder persönlich, telefonisch oder per Videokonferenz abgehalten werden (je nach Ihren Möglichkeiten und Präferenzen). Das Gespräch dauert maximal eine Stunde und wird von einer Doktorandin der Medizinischen Universität Graz durchgeführt und ausgewertet. Im Gespräch werden auch Daten wie Geschlecht, Beruf und Berufserfahrung abgefragt. Alle diese Daten werden streng vertraulich behandelt. Auswertungen erfolgen anonym – es werden keine Auswertungen für Einzelpersonen durchgeführt.

4. Worin liegt der Nutzen einer Teilnahme am Leitfadengespräch?

Mit Ihrer Teilnahme leisten Sie einen wichtigen wissenschaftlichen Beitrag.

5. Kann die Teilnahme am Leitfadengespräch vorzeitig beendet werden?

Ihre Teilnahme am Leitfadengespräch ist freiwillig und Sie können jederzeit, auch ohne Angabe von Gründen, Ihre Teilnahme abbrechen. Sie haben ebenfalls das Recht, die Verarbeitung Ihrer gesamten Daten jederzeit und ohne Angabe von Gründen zu widerrufen; in diesem Fall werden sämtliche Daten datenschutzrechtskonform vernichtet.

6. Datenschutz

Im Rahmen dieses Dissertationsprojektes werden Daten über Sie erhoben und verarbeitet. Grundsätzlich ist zwischen folgenden Daten zu unterscheiden:

1) Personenbezogenen Daten, anhand derer Sie direkt identifizierbar sind (z.B. Name, Geburtsdatum, Adresse)
2) Pseudonymisierten (verschlüsselten) personenbezogenen Daten, bei denen alle Informationen, die direkte Rückschlüsse auf Ihre Identität zulassen, durch einen Code (z. B. eine Zahl) ersetzt werden. Dies bewirkt, dass die Daten ohne Hinzuziehung zusätzlicher Informationen und ohne unverhältnismäßig großen Aufwand nicht mehr Ihrer Person zugeordnet werden können
3) Anonymisierten Daten, bei denen eine Rückführung auf Ihre Person nicht mehr möglich ist.

Zugang zu den Daten, anhand derer Sie direkt identifizierbar sind, haben die Doktorandin und die Mitglieder*innen des Dissertationskomitees. Die Daten sind gegen unbefugten Zugriff geschützt. Die Audioaufnahmen der Leitfadengespräche werden mit Projektende gelöscht.

Eine Weitergabe der Daten erfolgt nur in verschlüsselter oder anonymisierter Form. Auch für etwaige Publikationen werden nur die verschlüsselten oder anonymisierten Daten verwendet.

Sämtliche Personen, die Zugang zu Ihren verschlüsselten und nicht verschlüsselten Daten erhalten, unterliegen im Umgang mit den Daten der Datenschutz-Grundverordnung (DSGVO) sowie den österreichischen Anpassungsvorschriften in der jeweils gültigen Fassung. Im Rahmen dieses Projektes ist keine Weitergabe von Daten in Länder außerhalb der EU vorgesehen.

Sie können Ihre Einwilligung zur Erhebung und Verarbeitung Ihrer Daten jederzeit widerrufen. Nach Ihrem Widerruf werden keine weiteren Daten mehr über Sie erhoben. Die bis zum Widerruf erhobenen Daten können allerdings weiter im Rahmen dieser Studie verwendet werden.

Aufgrund der gesetzlichen Vorgaben haben Sie außerdem, sofern dies nicht die Durchführung des Projektes voraussichtlich unmöglich macht oder ernsthaft beeinträchtigt, das Recht auf Einsicht in die Ihre Person betreffenden Daten und die Möglichkeit der Berichtigung, falls Sie Fehler feststellen.

Sie haben auch das Recht, bei der österreichischen Datenschutzbehörde eine Beschwerde über den Umgang mit Ihren Daten einzubringen (www.dsb.gv.at).

Die voraussichtliche Dauer des Projektes ist bis Ende 2025. Die Dauer der Speicherung Ihrer Daten über das Ende des Projektes hinaus ist durch Rechtsvorschriften geregelt.

Falls Sie Fragen zum Umgang mit Ihren Daten in diesem Projekt haben, wenden Sie sich zunächst an die Projektverantwortliche. Dieser kann Ihr Anliegen ggf. an die Personen, die für den Datenschutz verantwortlich sind, weiterleiten.

Datenschutzbeauftragte/r des Prüfzentrums: datenschutz@medunigraz.at

7. Möglichkeit zur Diskussion weiterer Fragen

Bei Fragen können Sie sich gerne direkt an die Doktorandin des Dissertationsprojektes wenden.

Kontaktperson/Doktorandin:
Medizinische Universität Graz: Cornelia Krenn, BSc, MSc
Institut: Institut für Allgemeinmedizin und evidenzbasierte Versorgungsforschung
E-Mail: cornelia.krenn@medunigraz.at
Tel.: 0316/385-73567

8. Einwilligungserklärung

Name der Teilnehmerin/des Teilnehmers (in Druckbuchstaben):

.....

Ich erkläre mich bereit, am Leitfadengespräch im Rahmen des Dissertationsprojektes zum Thema „Nutzerzentrierte Adaptionsmöglichkeiten in Gesundheitsinformationen“ teilzunehmen. Ich erkläre mich bereit, dass das Leitfadengespräch aufgenommen wird und bin darüber informiert, dass die Audioaufnahme mit Projektende gelöscht wird.

Ich bin von der Projektverantwortlichen ausführlich und verständlich über den Zweck, Ablauf, Datenschutz sowie Freiwilligkeit zur Teilnahme an dem Projekt aufgeklärt worden. Ich habe darüber hinaus die Informationen zur Studie und Einwilligungserklärung, die insgesamt 4 Seiten umfasst, gelesen. Aufgetretene Fragen wurden mir verständlich und genügend beantwortet. Ich hatte ausreichend Zeit, um mich für die Teilnahme an dem Gespräch zu entscheiden. Ich habe zurzeit keine weiteren Fragen.

Ich werde den Anordnungen, die für die Durchführung des Projektes erforderlich sind, Folge leisten, behalte mir jedoch das Recht vor, meine freiwillige Mitwirkung jederzeit zu beenden, ohne dass mir daraus Nachteile für mich entstehen.

Ich stimme ausdrücklich zu, dass meine im Rahmen dieses Projektes erhobenen Daten wie im Abschnitt „Datenschutz“ dieses Dokuments beschrieben verwendet werden.

.....

(Datum und Unterschrift der Teilnehmerin/des Teilnehmers)

(Der/Die Interviewpartner*in erhält eine unterschriebene Kopie der Informationen zum Projekt und Einwilligungserklärung, das Original verbleibt im Studienordner der Projektverantwortlichen.)

Appendix 5 - Preliminary overview of customization options

Main category	Customization Option	Print media	Electronic media
Language Customization	Additional language	✓	✓
	Plain language	✓	✓
	Easy-to-read language	✓	✓
	Culture-sensitive language	✓	✓
	Sign language	⊗	A-V
	Translation of subtitles and captions	⊗	A-V
Presentation Customization	Same information presented in different visualization types	✓	✓
	Same information presented in different levels of detail	✓	✓
	Filtering and prioritizing of information	⊗	✓
	Special features	✓	✓
Text Customization *	***Text layout***	⊗	✓
	Perceiving (color, text size, text style, font, capitalization, character edge style, screen masking)	⊗	✓
	Tracking (line length, hyphenation, column)	⊗	✓
	Spacing (lines, letters, words, justification, margins and borders)	⊗	✓
	Text-to-speech	⊗	✓
	Read aloud only	⊗	✓
	Highlighted read-aloud text	⊗	✓
	Automatic scrolling of reading text	⊗	✓
	Reading speed	⊗	✓
	Reading volume	⊗	✓
Audio-visual Customization *	Audio description	⊗	A-V
	Text video description	⊗	A-V
	Audio transcription (speech-to-text)	⊗	A-V
	Table of contents	⊗	A-V
	Subtitles and captions	⊗	A-V
	Enhanced captions/subtitles	⊗	A-V
	Clean audio	⊗	A-V
	Playback speed	⊗	A-V

A-V refer only to audio-visual health information; ✓ implementation possible; ⊗ implementation not possible; * tools included in Web Content Accessibility Guideline 2.1 (WCAG)

Appendix 6 - COREQ checklist

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal Characteristics			
Interviewer/ facilitator	1	Which author/s conducted the interview or focus group?	Pg 25, Survey method
Credentials	2	What were the researcher's credentials? E.g., PhD, MD	Cover page
Occupation	3	What was their occupation at the time of the study?	na
Gender	4	Was the researcher male or female?	Cover page
Experience and training	5	What experience or training did the researcher have?	Pg 25, Survey method
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	Pg 43, paragraph 1
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research?	Pg 29, Interview process and documentation
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Pg 25, Survey method
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Pg 26, Interview guide
Participant selection			
Sampling	10	How were participants selected? e.g., purposive, convenience, consecutive, snowball	Pg 27, Recruitment
Method of approach	11	How were participants approached? e.g., face-to-face, telephone, mail, email	Pg 29, Interview process and documentation
Sample size	12	How many participants were in the study?	Pg 43, paragraph 1
Non-participation	13	How many people refused to participate or dropped out? Reasons?	Pg 43, paragraph 4
Setting			
Setting of data collection	14	Where was the data collected? e.g., home, clinic, workplace	Pg 43, paragraph 4
Presence of nonparticipants	15	Was anyone else present besides the participants and researchers?	Pg 43, paragraph 4
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	Pg 43, paragraph 5 + Table 7

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Data collection			
Interview guide	17	Were questions, prompts, and guides provided by the authors? Was it pilot tested?	Pg 26, Interview guide
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	Pg 43, paragraph 1
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	Pg 29, paragraph 2
Field notes	20	Were field notes made during and/or after the interview or focus group?	Pg 31, paragraph 1
Duration	21	What was the duration of the interviews or focus group?	Pg 43, paragraph 4
Data saturation	22	Was data saturation discussed?	Pg 123, paragraph 3
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	Pg 43, paragraph 4, Pg 123, paragraph 3
Domain 3: Analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	Pg 30, Data analysis
Description of the coding tree	25	Did the authors provide a description of the coding tree?	Pg 32, Table 3
Derivation of themes	26	Were themes identified in advance or derived from the data?	Pg 30-32, Data analysis
Software	27	What software, if applicable, was used to manage the data?	Pg 29, paragraph 3
Participant checking	28	Did participants provide feedback on the findings?	Pg 124, Critical reflection
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g., participant number	Yes, Pg 55, 66-67, 95-96, 106-107
Data and findings consistent	30	Was there consistency between the data presented and the findings?	Yes, Results 'Experiences of publishers of CHI'
Clarity of major themes	31	Were major themes clearly presented in the findings?	Yes, Results 'Experiences of publishers of CHI'
Clarity of minor themes	32	Is there a description of diverse cases or a discussion of minor themes?	No

Abbreviation: CHI = consumer health information; na = not applicable