

HEALTH LITERACY: WHAT LESSONS CAN BE LEARNED FROM THE EXPERIENCES OF OTHER COUNTRIES?



HEALTH LITERACY: WHAT LESSONS CAN BE LEARNED FROM THE EXPERIENCES OF OTHER COUNTRIES?

KARIN RONDIA, JEF ADRIAENSSENS, STEPHAN VAN DEN BROUCKE, LAURENCE KOHN



Title:	Health literacy: what lessons can be learned from the experiences of other countries?
Authors:	Karin Rondia (KCE), Jef Adriaenssens (KCE), Stephan Van Den Broucke (UC Louvain), Laurence Kohn (KCE)
Project facilitator:	Nathalie Swartenbroekx (KCE)
Senior supervisor:	Christian Leonard (KCE)
Reviewers:	Pascale Jonckheer (KCE), Nancy Thiry (KCE)
Stakeholders:	Jean-Michel Antonutti (SPFB – Service public francophone bruxellois, COCOF – Commission communautaire française), Fabrizio Cantelli (LUSS – Ligue des usagers des services de santé), Emmanuelle Caspers (SPFB – Service public francophone bruxellois, COCOF – Commission communautaire française), Karin Cormann (DGOV – Communauté germanophone), Maïté Cuvelier (Cultures et santé), Yves Dario (Koning Boudewijnstichting – Fondation Roi Baudouin), Valerie Fabri (UNMS - Union Nationale des mutualités Socialistes), Marleen Finoulst (Cebam, Gezondheid en Wetenschap), Siska Germonpré (NVSM – Nationaal Verbond van Socialistische Mutualiteiten), Claire Huyghebaert (UNML – Union Nationale des Mutualités Libres), Denis Mannaerts (Cultures et santé), Emmanuelle Nijs (Koning Boudewijnstichting – Fondation Roi Baudouin), Maryse Van Audenhaege (Landsbond der Christelijke Mutualiteiten), Martine Van Hecke (Test Aankoop), Tinne Vandesande (Koning Boudewijnstichting – Fondation Roi Baudouin), Rebekka Verniest (Landsbond der Christelijke Mutualiteiten)
External validators:	Gilles Henrard (ULg – Université de Liège), Diane Levin-Zamir (Clalit Health Services, Israel), Orkan Okan (Universität Bielefeld)
Acknowledgements:	Jamie Begbie (Health Literacy Policy Lead Scottish Government, Scotland), Christina Dietscher (Bundesministerium für Arbeit, Soziales, Gesundheit und Konsumentenschutz, Austria), Frank Doyle (Royal College of Surgeons, Ireland), Helen Kelly (Royal College of Surgeons, Ireland), Naomi Poole (Australian Commission on Safety and Quality in Health Care, Australia), Jany Rademakers (NIVEL, the Netherlands), Helen Ryan (The National Adult Literacy Agency – NALA, Ireland), Miguel Telo de Arriaga (Divisão de Estilos de Vida Saudável na Direção-Geral da Saúde, Portugal), Filipa Ventura (Escola Superior de Enfermagem de Coimbra Portugal)
Reported interests:	'All experts and stakeholders consulted within this report were selected because of their involvement in the topic of Health literacy. Therefore, by definition, each of them might have a certain degree of conflict of interest to the main topic of this report'
	Membership of a stakeholder group on which the results of this report could have an impact: Valérie Fabri (UNMS), Siska Germonpré (Staff member NVSM), Martine Van Hecke (Test Aankoop)



Participation in scientific or experimental research as an initiator, principal investigator or researcher: Tine Vandesinde (Selection of health literacy projects supported by the Fonds Daniël De Coninck)

Layout:

Joyce Grijseels, Ine Verhulst

Disclaimer:

- The external experts were consulted about a (preliminary) version of the scientific report. Their comments were discussed during meetings. They did not co-author the scientific report and did not necessarily agree with its content.
- Subsequently, a (final) version was submitted to the validators. The validation of the report results from a consensus or a voting process between the validators. The validators did not co-author the scientific report and did not necessarily all three agree with its content.
- Finally, this report has been approved by common assent by the Executive Board.
- Only the KCE is responsible for errors or omissions that could persist. The policy recommendations are also under the full responsibility of the KCE.

Publication date:

9 januari 2020

Domain:

Health Services Research (HSR)

MeSH:

Health Literacy, Policy

NLM Classification:

WA 590

Language:

English

Format:

Adobe® PDF™ (A4)

Legal depot:

D/2019/10.273/63

ISSN:

2466-6459

Copyright:

KCE reports are published under a “by/nc/nd” Creative Commons Licence
<http://kce.fgov.be/content/about-copyrights-for-kce-publications>.





How to refer to this document?

Rondia K, Adriaenssens J, Van Den Broucke S, Kohn L. Health literacy: what lessons can be learned from the experiences of other countries? Health Services Research (HSR) Brussels: Belgian Health Care Knowledge Centre (KCE). 2019.KCE Reports 322. D/2019/10.273/63.

This document is available on the website of the Belgian Health Care Knowledge Centre.



TABLE OF CONTENTS

1	HEALTH LITERACY	9
1.1	HEALTH LITERACY: AN EVOLVING CONCEPT	9
1.2	MEASURING HEALTH LITERACY	11
1.3	HEALTH LITERACY AND PUBLIC HEALTH	12
1.4	EXISTING RECOMMENDATIONS FOR HEALTH LITERACY POLICIES IN EUROPE	13
1.4.1	WHO Solid Facts report	13
1.4.2	IROHLA project	14
1.4.3	HEALIT4EU Project.....	16
1.4.4	WHO Health Evidence network.....	17
1.5	CAPACITY BUILDING.....	17
1.5.1	Knowledge development	19
1.5.2	Workforce development	19
1.5.3	Organisational and institutional capacity.....	20
1.5.4	Partnerships	21
1.5.5	Financial and non-financial resources.....	21
1.5.6	Governance and leadership	21
2	MATERIALS AND METHOD	22
2.1	GOAL OF THE STUDY	22
2.2	DESIGN OF THE STUDY.....	22
2.3	IDENTIFICATION OF HEALTH LITERACY POLICIES AND INITIATIVES IN BELGIUM	22
2.4	TRANSVERSAL ANALYSIS OF FOREIGN HEALTH LITERACY POLICIES	23
2.4.1	Choice of the countries.....	23
2.4.2	Development of the analytical grid	23
2.4.3	Data collection method.....	23



2.5	FORMULATION OF RECOMMENDATIONS FOR A BELGIAN ACTION PLAN	24
3	HEALTH LITERACY IN BELGIUM	24
3.1	THE LEVEL OF HEALTH LITERACY IN BELGIUM	24
3.1.1	2014 – Study of the Christian Health Insurance Fund	24
3.1.2	2018 – Sciensano National Health Survey.....	25
3.1.3	Other studies from the Health Insurance Funds	26
3.2	CURRENT HEALTH LITERACY POLICY IN BELGIUM	27
3.2.1	Health in all policies – Charter in Flanders (2003)	27
3.2.2	Recommendations on Health Literacy from the (Flemish) Royal Academy of Medicine (Koninklijke Academie voor Geneeskunde van België -KAGB) (2014)	27
3.2.3	RIZIV – INAMI White paper (2014)	27
3.2.4	Mention in the federal coalition agreement of 9 October 2014	28
3.2.5	FPS Public Health management agreement 2016 – 2018.....	28
3.2.6	The Flemish Charter of the rights of the patient/client (SAR-WGG) (2017).....	28
3.2.7	Advice of the Flemish Strategic Advisory Board Well-being Health Family (SAR-WGG) (2017)	28
3.2.8	Motion for a resolution to introduce an Action Plan to significantly improve the Health Literacy of Belgians (2018)	29
3.2.9	The strategic plan for health promotion 2018/2022 of the French-speaking government of Brussels.....	29
3.3	EXISTING INITIATIVES ON THE FIELD	30
3.3.1	Heerlijk Helder in de Zorg (expertisecentrum MEMORI, Thomas More, 2016).....	30
3.3.2	Littérature en santé (Culture & Santé ASBL, Octobre 2016).....	30
3.3.3	Oog voor gezondheidsvaardigheden (VIGEZ, 2016).....	30
3.3.4	The Well Done MSD Health Literacy Awards (until 2017) and MSD HealthNest (from 2018).....	31
3.3.5	Gezondheid en Wetenschap	31



	3.3.6	Mon Généraliste.be	31
	3.3.7	MondocMasanté / MijnthuisdokterMijngezondheid	32
	3.3.8	The Dr Daniël De Coninck Fund steered by the King Baudouin Foundation (2018)	32
	3.3.9	The health insurance funds	32
	3.3.10	Efforts of the Belgian patient representative platforms	33
	3.3.11	Test Gezond / Test Santé	33
	3.3.12	The communities and the civil society.....	33
4		INTERNATIONAL COMPARISON	33
4.1		BACKGROUND OF THE HL PLANS	34
	4.1.1	Low levels of HL	34
4.2		DEVELOPMENT OF THE HL PLANS	36
	4.2.1	Initiation of the HL Plans	36
	4.2.2	Political contexts of the studied policies and action plans	38
	4.2.3	Methods used to develop and to run the HL action plans and policies.....	39
	4.2.4	Financial resources	42
4.3		CONTENT OF THE HL ACTION PLANS AND POLICIES.....	43
	4.3.1	Beneficiaries of the action plans and policies	43
	4.3.2	Announced goals and strategies.....	43
	4.3.3	Actors	45
	4.3.4	Partnerships	46
	4.3.5	Actions.....	47
4.4		IMPLEMENTATION.....	49
	4.4.1	Timing.....	49
	4.4.2	Opportunities	49



	4.4.3	Threats	50
4.5		EVALUATION OF THE HL POLICIES AND PLANS	50
4.6		MONITORING OF HEALTH LITERACY	52
4.7		IMPACT OF THE HL ACTIONS PLANS AND POLICIES	52
5		OPTIONS FOR A BELGIAN HEALTH LITERACY POLICY PLAN	53
5.1		HEALTH LITERACY CAPACITY BUILDING FOR BELGIUM	53
	5.1.1	Governance	54
	5.1.2	Knowledge development	55
	5.1.3	Workforce development	55
	5.1.4	Organisational and institutional capacity	56
	5.1.5	Partnerships	56
	5.1.6	Financial and non-financial resources	57
5.2		THREE POSSIBLE PATHS	57
	5.2.1	Conceptual?	57
	5.2.2	Pragmatic?	58
	5.2.3	Or no plan at all?	58
6		CONCLUSIONS	59
6.1		FIRST, SET THE STAGE FOR A NATIONAL ACTION PLAN	60
6.2		THEN CONSIDER THE FOLLOWING INTERVENTIONS	60
	6.2.1	Governance	60
	6.2.2	Workforce development	61
	6.2.3	Partnerships	61
	6.2.4	Organisational and institutional capacities	61



LIST OF FIGURES

Figure 1 – The two components of Health Literacy	10
Figure 2 – Levels of general health literacy (HL) index by country and for the total sample, based on the HLS-EUQ	12
Figure 3 – Conceptual framework for public health capacities ³⁴	18
Figure 4 – Levels of health literacy according to the region in Belgium	25
Figure 5 – Questions related to health literacy in the Health Survey 2018.....	26

LIST OF TABLES

Table 1 – Scope of the studied HL action plans	33
Table 2 – Overview of the HL levels of the studied countries	34
Table 3 – Initiative of the studied HL action plans	37



LIST OF ABBREVIATIONS

ABBREVIATION	DEFINITION
ABS	Australian Bureau of Statistics
ACSQHC	Australian Commission on Safety and Quality in Health Care
ALLS	Adult Literacy and Lifeskills Survey
ASBL	Association Sans But Lucratif
AT	Austria
AUS	Australia
BVAS – ABSyM	Belgische Vereniging van Artsensyndicaten – Association Belge des Syndicats Médicaux
CEBAM	Center of Evidence-Based Medicine
CM – MC	Christelijke Mutualiteit – Mutualité Chrétienne
COCOF	Commission Communautaire Française de la Région Bruxelles-Capitale
CompHP	Core Competencies Framework for Health Promotion
DGGS	Directora(a)t Genera(a)l Gezondheidszorg/Soins de Santé
EBP	Evidence-based practice
EHII	Europe's Health Information Initiative
EU	European Union
FPS	Federal Public Service
FWB	Fédération Wallonie-Bruxelles
GP	General Practitioner
HiAP	Health in All Policies approach
HIS	Health Interview Survey
HL	Health literacy
HLS-EU	The European Health Literacy Survey
HSE	Health Service Executive (Ireland)
IALS	International Adult Literacy Surveys
IE	Ireland



IROHLA	Intervention Research On Health Literacy of the Ageing population in Europe
IUHPE	International Union for Health Promotion and Education
KAGB	Koninklijke Academie voor Geneeskunde van België
LUSS	Ligue des Usagers des Services de Santé
MAGIC	MAking Good decisions In Collaboration
MR	Mouvement Réformateur
MSD	Merck Sharp and Dohme
NALA	National Adult Literacy Agency
NALS	National Adult Literacy Survey
NCD	Non-Communicable Diseases
NED	The Netherlands
NGO	Non-Governmental Organisation
NHLAG	National Health Literacy Action Group
NIGZ	Nationaal Instituut voor Gezondheidsbevordering en Ziektepreventie
NIH	National Institute of Health
NSQHS	National safety and quality health service
NSQHS	National Safety and Quality Health Service
NVA	Nieuw-Vlaamse Alliantie
OECD	Organisation for Economic Co-operation and Development
OEPGK	Österreichische Plattform Gesundheitskompetenz
Open-VLD	Open Vlaamse Liberalen en Democraten
Org-HLR	Organisational Health Literacy Responsiveness Assessment
PIAAC	Programme for the International Assessment of Adult Competencies
POR	Portugal
PRT	Patient Rat & Treff
RIZIV – INAMI	Rijksinstituut voor Ziekte- en Invaliditeitsverzekering – Institut National d'Assurance Maladie-Invalidité



SAR-WGG	Strategische Adviesraad voor het Vlaamse Welzijns-, Gezondheids- en Gezinsbeleid
SCOT	Scotland
SCVO	Scottish Council for Voluntary Organisations
SHLAPIG	Scottish Health Literacy Action Plan Implementation Group
SNS	Serviço Nacional de Saúde
SSMG	Société Scientifique de Médecine Générale
UCL	Université Catholique de Louvain
V-HLO	Vienna Concept of Organisational Health Literacy
VIGeZ	Vlaams Instituut voor Gezondheidspromotie en Ziektepreventie
VPP	Vlaams Patiëntenplatform
WHO	World Health Organisation

■ SCIENTIFIC REPORT

1 HEALTH LITERACY

1.1 Health literacy: an evolving concept

In 1978 Leonard and Cecile Doak (often considered as the founders of health literacy, although they did not introduce the term) studied the reading skills of hospitalized patients. The Doaks, along with Jane Root, co-authored the landmark book “Teaching Patients with Low Literacy Skills”, which was first published in 1985.¹ In the early nineties of the last century, a national working group on health literacy was set up in the NIH National Cancer Institute in the United States. This was one of the first initiatives regarding health literacy where experts of different fields (healthcare, education, social sciences) were brought together.² From that moment on, several government agencies worldwide started to sponsor health literacy related initiatives.

In the early nineties of the past century, several studies, originating from the educational sciences field (e.g. National Adult Literacy Survey (NALS; 1992) and International Adult Literacy Surveys (IALS; 1994)) were conducted on adult literacy (in general). These studies revealed problematic findings of limited literacy among large shares of the population in many countries.³ These results were confirmed by more recent surveys (e.g. the OECD Programme for the International Assessment of Adult Competencies (PIAAC, 2011)⁴ and the Adult Literacy and Lifeskills Survey (ALLS, 2003-2008⁵). These studies also showed that the level of literacy is influenced by a variety of social factors and that an increase of literacy is related to more opportunities in life, higher levels of employment and more social engagement. These findings led to the perception of literacy as a contributor to health outcomes and as a mediating factor in health disparities.

In the late nineties and the first decade of the twenty-first century, a broad range of studies was conducted on relationships between literacy (in general) and health outcomes (in terms of knowledge, behaviour, morbidity and mortality).⁶ Much of the literature in this field of research has focused on the serious problems that people with low health literacy face when interacting with healthcare systems (limited participation in health promotion, disease prevention and early detection, inadequate



management of chronic diseases, increased hospitalisation rates, and higher odds for rehospitalisation).³ The same studies revealed that health literacy must be conceived as a much broader concept, as not only reading and writing skills are important to access and interact with the healthcare system. People with low health literacy have problems with establishing contacts with healthcare professionals, accessing healthcare institutions, taking up their part in health related shared decisions, understanding the pathophysiology of a health condition, following treatment instructions, or taking up responsibility for their own health.

While early definitions of health literacy were mainly focused on the patient and his/her skills to access and understand the healthcare system, recent studies put more emphasis on skills, knowledge and approaches to function in the healthcare context in which the patient moves, i.e. the match between the demands of the care system in terms of health information and a person's literacy.³ This is equivalent to switching from an 'individual deficit model' perspective to a more system-wide asset model.⁷ or, as Ancker recently pointed: "The ability to use health information in the service of health is an emergent property of a system, not simply a function of individual skills."⁸ Characteristics like gender, age, educational level, perceived health status, socio-economic status, self-confidence, cultural and social environment have an influence on a person's level of health literacy⁹, but the way healthcare is organised and the way information about health is conceived and communicated are other key factors on the side of the system. A complex healthcare system makes it more difficult for its users to act as health literate persons.¹⁰ Health literacy becomes thus **a shared responsibility of both individuals and healthcare organisations**, and a swing in the emphasis in policy from health promotion to health system reform approaches has also been observed.¹¹

Figure 1 – The two components of Health Literacy



Source: Parker R, *Measuring health literacy: Why? So what? Now what?* In: Hernandez L (ed), *Measures of Health Literacy: Workshop Summary; Roundtable on Health Literacy*. 2009.

This broader view of health literacy as **an interaction between a patient and his or her health context** is well reflected in Sørensen, Van den Broucke, Fullam et al's definition of health literacy as "*people's knowledge, motivation and competencies to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course.*"¹² This definition takes other key variables and players into account, gives opportunities for the development of new measures, and calls for more complex analyses. Moreover, it opens doors to setup multi-dimensional intervention programs or policies, taking into account all the aspects of health literacy.

As a consequence of this – now widely accepted – definition, the ways to improve health literacy have also expanded from interventions targeting individuals to ones aimed at the whole healthcare system. Murugesu, Heijmans, Fransen & Rademakers¹³ propose three levels of action:

- **Micro-level** is the direct interaction between the health (and social) care professional and the patient. This is not limited to the fact that the patient has to understand the information given by the professional, but also implies that he/she is made able to fully engage in prevention, decision-making, and self-management. It is of utmost importance to make it clear that providing solely simple, understandable and reliable



information is not sufficient; patients have to be supported so that they feel that they can and want to use that knowledge. Health professionals have to be trained to address the power imbalance between them and their patients in order to really empower them.¹⁴

- **Meso-level** concerns the organisation of care at the level of the institution as well as of the private practice. This includes, for example, the friendliness of the appointment system, the wayfinding signalisation in hospitals, the comprehensibility of the available information material, the availability of user-friendly eHealth and ICT tools, etc. The training of the healthcare workforce in that respect is of paramount importance. This level is also called “organisational health literacy” and much research has been done on this topic this last decade.
- **Macro-level** includes the general framework conditions for putting health literacy in all sectors of the society: health policies at all political levels and inter-sectoral approaches (e.g. involving the education sector, the workplaces, the media, the alimentary sector, etc.), as well as within the health system (commitment of the health insurers, participation of professional associations, etc.).

1.2 Measuring Health Literacy

The broader the definition of health literacy, the more difficult it is to measure it, because it encompasses concepts that are very difficult to quantify. This explains why until recently, efforts were mainly focused on measuring the health literacy of individuals in a ‘narrow’ sense (e.g. how do they understand leaflets, brochures and medication labels). However, new tools have recently been developed that can capture more comprehensive conceptualisations of health literacy and include other skills (e.g. communication, critical thinking) and dimensions (e.g. motivation, social support). Since these skills and dimensions seem essential for the effectiveness of health literacy interventions that aim at behavioural change, the use of such instruments is now recommended.¹⁵

Measures of health literacy also vary according to the aim of the measurement. For example, measuring a person’s individual health literacy in the context of clinical practice can be done (very approximately) during a

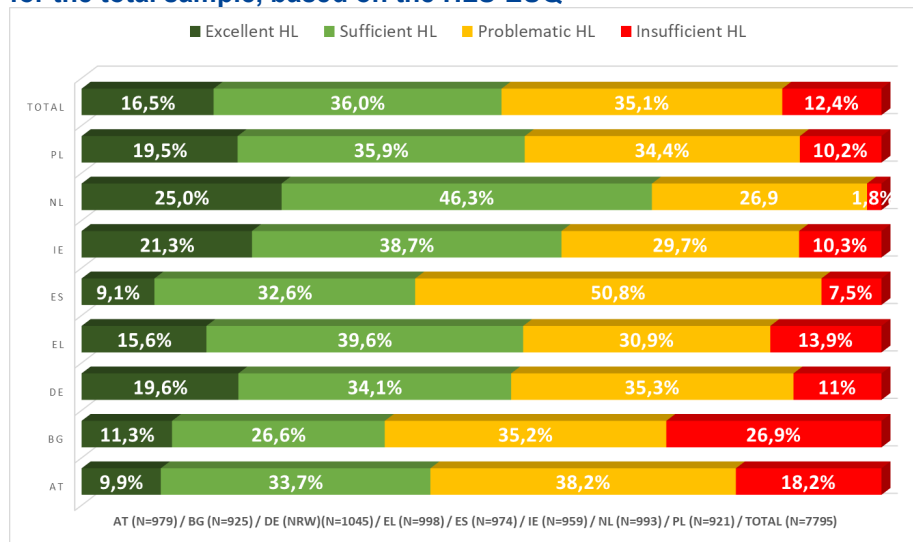
consultation by means of a brief test or questionnaire. More detailed tools can be used at the level of organisations, for instance when a hospital wants to assess the level of health literacy of its patients (for instance to target appropriate education and support programmes). And finally, scientists and policy makers can call on population-based surveys to document the level of health literacy within the population of a country. An up to date overview of the abovementioned instruments can be found at <https://healthliteracy.bu.edu/>.

Tools are also being developed to assess the health literacy friendliness of healthcare institutions (e.g. how easily do people find their way in a hospital, how much do they understand about the care they receive or the amount they have to pay, etc.). Well known examples of such tools are Enliven, Org-HL and V-OHL. These tools are important to assess the health literacy at an organisational level, and to promote awareness, identify strengths and areas for improvement, and gain consensus for prioritizing health literacy interventions.¹⁶ They will be further detailed in section 1.5.

Regarding large population surveys, the best-known example is the European health literacy survey (HLS-EU) which was conducted in eight countries: Austria, Bulgaria, Germany, Greece, Ireland, the Netherlands, Poland and Spain. The questionnaire that was used for this survey was based on the conceptual model of health literacy developed by Sørensen *et al.*¹² and validated for all eight the participating countries. It contained 47 items. The results distinguished four levels of health literacy: excellent, sufficient, problematic and insufficient. Across the countries that participated in the survey, at least 1 in 10 (12%) of the respondents showed insufficient health literacy and almost 1 out of 2 (47%) had limited (insufficient or problematic) health literacy. However, the distribution of levels differed substantially between countries (29–62%). The survey also identified subgroups with higher proportions of people who had limited health literacy, such as persons with a low social status, low education or old age. The study concluded that limited health literacy represents an important challenge for health policies and practices across Europe, but to a different degree for different countries, and that the social gradient in health literacy must be taken into account when developing public health strategies to improve health equity in Europe.¹⁷



Figure 2 – Levels of general health literacy (HL) index by country and for the total sample, based on the HLS-EUQ



Sorensen et al, 2015¹⁷

1.3 Health literacy and Public health

The figures in the former section show that low health literacy is not just a problem of a small minority, but that a significant part of the population suffers from limited or even insufficient skills to access, understand, appraise and/or apply information they need to make decisions concerning their health. Consequently, the importance of health literacy in public health policies is increasingly recognised.

Low health literacy affects the people across their whole lifespan and has consequences that go far beyond the mere fact of “not understanding what the doctor says”. It is now well demonstrated that health literacy is essential to successful access to healthcare, to effective use of healthcare services, to adequate self-care of chronic conditions, and to the maintenance of health and wellness. It is also known that people with low levels of health literacy

are more likely to report a sense of shame about their skill level¹⁸, which is likely to reduce interaction with health and social care services.¹⁹

With the growing trend towards self-management, partnership with the patient and shared decision making, individuals are required to take up a more active role in the management of their own health condition. This active role implies that they have a sufficient level of health literacy.

It is also well known that vulnerable groups like the elderly and the chronically ill are most at risk of having insufficient health literacy, while they are the ones with the greatest healthcare needs and expenses. Evidence shows that people with low health literacy are at risk for inadequate health-related behaviour, health service use, treatment and medication adherence, and self-care management.²⁰, and that they have higher mortality rates, are less likely to use preventive health services, and have difficulty navigating the healthcare system. A Belgian study also showed that low health literacy is associated with greater use of health care services, particularly the more specialised services.²¹ A systematic review showed that people with low health literacy are between 1.5 and 3 times more likely to experience an adverse outcome.²² In brief, “*low health literacy ‘significantly drain[s] human and financial resources in the health system’*.”²³

Consequently, health literacy has been recognised as a critical determinant of health in several international key political statements at European and global levels. The WHO 2016 Shanghai Declaration on promoting health in the 2030 Agenda for Sustainable Development²⁴ commits to “*develop, implement and monitor inter-sectoral national and local strategies for strengthening health literacy in all populations and in all educational settings; increase citizens’ control of their own health and its determinants, through harnessing the potential of digital technology; ensure that consumer environments support healthy choices through pricing policies, transparent information and clear labelling.*” (WHO 2016 Shanghai Declaration on promoting health in the 2030 Agenda for Sustainable Development²⁴, p 2). Health literacy is also recognised as a key component of the European health policy framework Health 2020, which contributes to reduce health inequities, strengthen public health and ensure people-centred health systems that are universal, equitable, sustainable and of high quality.²⁵



A recent Belgian integrative review of 16 studies exploring socioeconomic and sociodemographic factors associated with low HL levels shed light on the mediating role of HL in the relationship between socioeconomic status and health disparities. By focusing on intermediate factors such as health literacy, strategies to reduce health inequalities will not lift people from disadvantaged socioeconomic conditions but can be considered as a 'midstream' strategy to reduce the impact of 'upstream' socioeconomic determinants on 'downstream' disparities in health.²⁶ Still health literacy needs to be promoted in adequacy with the characteristics and the needs of the targeted public, adopting a proportionate universalism approach^a.²⁷ This means that the content and the form of the communication to the different populations must always take into account different cultural, educational and socioeconomic features and levels. In the present time, this means that also the media and the digital media must be paid great attention to.²⁸

1.4 Existing recommendations for Health Literacy policies in Europe

1.4.1 WHO Solid Facts report

Shortly after the publication of the HLS-EU study (2012), health literacy started being addressed through policies or activities in a growing number of countries. In 2013, the WHO Regional Office for Europe published a **WHO Solid Facts report**²³ to distil the best available evidence on health literacy and to describe the policy implications and action points that are needed to improve the situation. This report highlighted a series of key action areas that could contribute to developing policies for health literacy on all levels. These action areas include:

- **Championing and leading for health literacy across society by:**
 - Partnerships with the existing networks, alliances and organisations that promote patient participation, public health and consumer rights;
 - Involvement of the private sector (e.g. for providing reliable information to patients and consumers);
 - Involvement of the mass media to contribute to better information, transparency and accountability for health;
 - **Involvement of the health sector that should lead by example, by creating enabling health care settings and training all health professionals in improving their communication skills;**
 - Involvement of the national health services and health insurers who can create incentives for action in the health sector to support health literacy;
 - Involvement of patient and consumer organisations who can advocate for greater patient involvement and health literacy-friendly health care settings.
- **Aligning with the values and principles of the public good:**
 - by recognising the right of everyone to health information and health systems that they can understand and navigate;
 - by reducing health inequities by means of targeted initiatives for vulnerable groups;
 - **by reducing societal costs through investing in health literacy at the level of national, regional or local governments;**

^a "Focusing solely on the most disadvantaged will not reduce health inequalities sufficiently. To reduce the steepness of the social gradient in health, actions must be universal, but with a scale and intensity that is proportionate to the level of disadvantage. We call this proportionate universalism."



- by building capacity to sustain change, because strengthening health literacy not only improves health but also builds resilience to help individuals and communities navigate their way to health-sustaining resources and actions.
- **Advocating to put health literacy on the public policy agenda:**
 - by **developing national and local strategies that strengthen health literacy, whether** as a separate strategy or as a part of other national strategies for health or education;
 - by integrating **standards for health-literate organisations in the quality management and corporate social responsibility of** institutions such as workplaces, schools, hospitals and retail outlets;
 - **by adopting a multidimensional approach with respect** to differences in cultures, gender, age and individuals.
- **Strengthening the evidence base of health literacy through support for research and monitoring:**
 - by investing in interdisciplinary research that demonstrates the benefits of tackling health literacy;
 - by conducting surveys of health literacy and the health literacy friendliness of systems at regular intervals to allow comparisons over time (also including children and adolescents);
 - by setting priorities in key developmental areas, such as analysing the effects of mass media and social media;
 - by expanding existing measures of health literacy oriented towards the individual to include the collective level (including communities) and to assess the literacy friendliness of materials, organisations and environments.
- **Working together at the European Region level.**

1.4.2 IROHLA project

In order to map the best practices to address the challenge of health literacy among elderly persons, the European Commission funded the Intervention Research On Health Literacy of the Ageing population in Europe (IROHLA) project from 2012 to 2015.²⁹⁻³¹ Funded within the 7th Framework Programme for Research, the project involved 22 partners of nine European countries (including Belgium). The starting point for the project was that health literacy is a dynamic concept, dependent on the context where it is applied. As ageing is often related to a higher prevalence of chronic diseases, the impact of health literacy can be even higher in older people than in a younger population. Therefore, the project focused on the production of a set of feasible interventions, guidelines and conditions aiming to improve health literacy among the elderly.

Research in the IROHLA project showed that better health literacy outcomes could be achieved when interventions take place in four areas:

- Empowerment of the older persons with low health literacy
- Strengthening the social support systems (personal network): family, caregivers, community
- Enhancing the communication and interaction competencies of health workers;
- Improving the health system, to become more accessible for all groups in society.

One of the conclusions of the IROHLA project was that incorporating health literacy in **all policies** in the area of health care or healthy ageing, is a precondition for effective health literacy intervention programmes. For example, public health programmes, as well as patient safety and health care quality programmes can benefit from easily understandable health information for the population and more accessible and acceptable e-health and m-health applications.



The project also focused on the necessary steps to implement health literacy in government policies. A first step is that national and regional governments should set the standards for accessibility to health promotion, prevention, cure and care. This focus on health literacy can be helpful to achieve sustainability and equity in healthcare. Secondly, a comprehensive health literacy approach should be strived for, not only focused on individuals and communities but also on health professionals and organisations. Although health literacy is often defined with a focus on abilities of individuals, health literacy outcomes are in fact the result of interactions between the stakeholders. Thirdly, a patient-centred approach in health care is needed as this has proven to be beneficial for healthcare outcomes. Patients, in the case of IROHLA the elderly, need to be empowered to take up their role in the interactive healthcare system. IROHLA defined a list of potentially modifiable determinants of knowledge, skills and attitudes which can be important for the improvement of health literacy in the ageing population. These determinants, focused on patient, society, healthcare professional and the health system, were based on social psychology, learning theory, systems theory and communication sciences.

The analysis part of project, based on in depth literature research, resulted in a list of 338 components in 56 interventions or clusters of intervention, from which 242 aimed at individuals and 96 at health professionals or the health system. The analysis resulted in the following recommendations:

- Use a patient empowering approach and pay attention to contextual factors that could be social, physical or cultural barriers.
- Apply repetition of the health-related messages and use of a variety of methods of follow-up after providing health information.
- Offer to individuals health literacy programmes with a mix of group work and individual follow-up for at least half a year. This will result in sustainable behavioural change.
- Make use of peer groups, buddies, volunteers, home visitors as they are instrumental in communication and skills (social network).
- Apply interactive E-health interventions (and take a step-by-step approach) for their effects on increasing health literacy.
- Lower or remove barriers (social, physically, culturally); they can make an important contribution from outside the health sector.
- Organise community-based interventions on the basis of co-creation between governmental and non-governmental stakeholders, as these are effective for sustainability.

Focusing on the policy level for health literacy, the IROHLA project states that:

- Policy briefs should respond to a felt need of the target audience, or in other words address actual problems encountered. This implies that HL policy has to be tailored to specific needs in the country or region.
- Policy briefs should be offering solutions that are within reach of the target audience, and should not aim for the highest (not-attainable) goals.
- Policy briefs should show evidence-based feasible actions, which produce quick wins and lead to further action rather than proposing long-lasting investments.
- Policy briefs should be offered a way that enables local changes as required by the context. General principles should be clear and opportunities for adjustments should be pointed out.
- And finally, policy brief should be presented in the right forums, and personal follow-up by decision-makers is necessary.



1.4.3 HEALIT4EU Project

In 2015, the **HEALIT4EU project**, based on a tender by the European Commission's Health Directorate, published a review of health literacy policies across Europe.¹⁵ The authors identified 82 policies, programmes and actions in EU Member States. However few of these interventions were coordinated through a national or a regional policy.

The broad conclusions were that:

- Health literacy as a concept gained attention in several EU Member States during the last years. However, in most countries, it was rarely used, used in a wider context of health promotion, or even unknown. Belgium was not in the top 5 of the European countries.
- Ten EU Member States – among which Belgium – did not have any policy, programme or substantial activity in the domain of health literacy. Eight were in early stages of policy making. Five seemed to have developed activities that fit all stages of the policy cycle.
- Six countries had a policy at national level on health literacy (Austria, Ireland, Italy, Portugal, Spain and United Kingdom).
- Current evidence did not enable to conclude whether policies, programmes and activities were effective or not.
- Many stakeholders seemed to be involved in health literacy. Universities and research and knowledge centres had an important contribution especially in the early stages of the policy cycle (problem definition and agenda setting).

The authors added that a coordinated policy did not seem to be a requirement for the development of programmes and activities on health literacy when stakeholders themselves are active in the development of such activities. Often both government and NGOs together initiate and conduct activities. In addition, national 'Networks' or National Working Groups on health literacy have an important advocacy role and act as a platform for exchange between research and practice.

The HEALIT4EU project came to the following recommendations:

For interventions:

- Future health literacy interventions and evaluations of these interventions in an EU context should use research designs which have sufficient scientific rigour;
- Future evaluation studies of health literacy interventions should encompass an evaluation of the cost-effectiveness of these interventions;
- Interventions should (a) be tailored to the needs of patients in general or groups with inadequate health literacy specifically and (b) address critical and/or interactive skills and competencies (and not only knowledge).

For research:

- There is a need for agreement among researchers on valid measurement tools for health literacy in a European context, and more systematic use of validated, preferably comprehensive, measurement tools in interventions;
- Health literacy research funding should give more attention to (a) the quality of the studies and (b) the need for specific kind of evidence, such as: intervention studies, effectiveness and cost-effectiveness, and international comparative research.

For policies:

- Health literacy is on the agenda in most of the EU Member States, but the efforts should be better coordinated through a policy at the most appropriate level;
- The concept of 'health literacy' can be considered a useful complement to more general health promotion and education policies, as it enables to better tailor health promotion and education approaches to



individuals or populations with low literacy and increase the effectiveness of such policies;

- Policies on health literacy should also address the context in which people have to be health literate.

1.4.4 WHO Health Evidence network

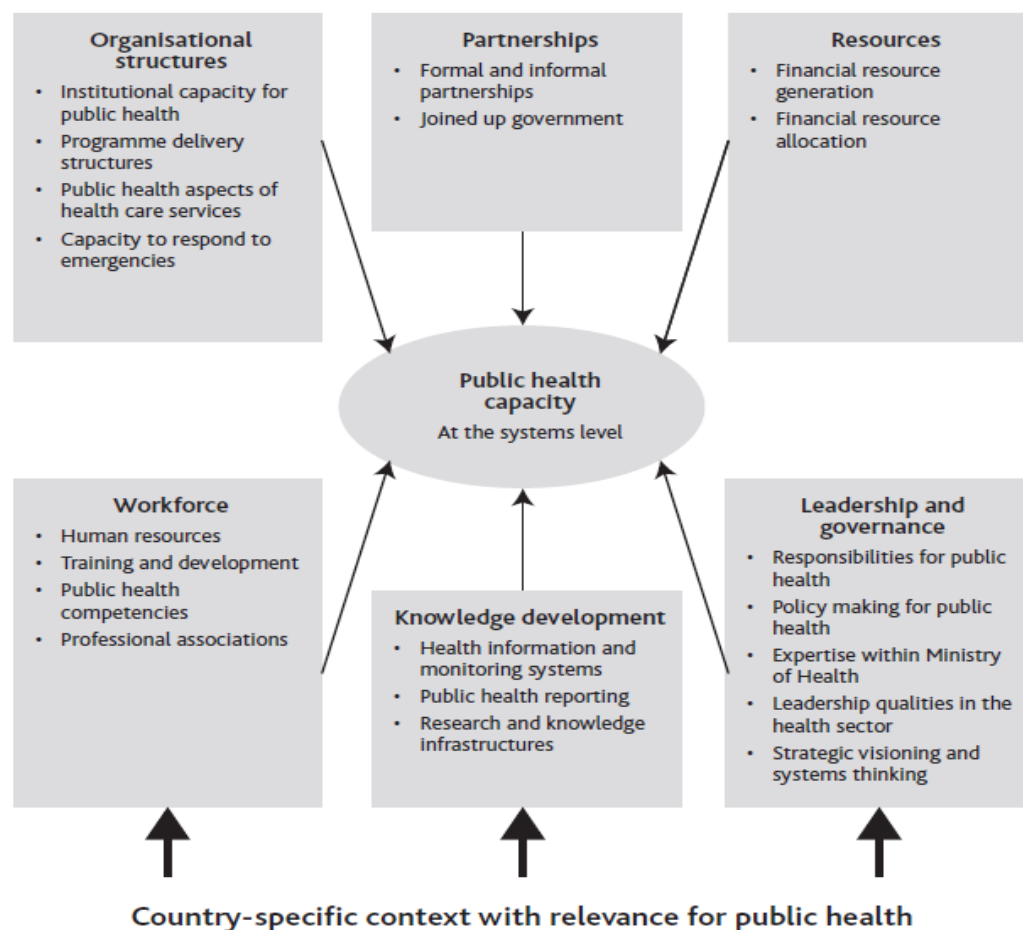
In 2018, the WHO Regional Office for Europe published a **review of the evidence underlying the existing Health Literacy policies in Europe**.³²

The conclusions and recommendations of this report should also be kept in mind when approaching this research on the best options for a Belgian HL Action Plan:

- consider the existing policies and related activities (gathered in this review) to develop or enhance health literacy policies and related activities to benefit citizens, patients and communities;
- broaden the range of areas of activity required for holistic health literacy policies to include the lived environment, the workplace, the media and digital/e-health, at all societal levels – individual, community, organization and system (legislative);
- strengthen the evidence base for health literacy at all societal levels to ensure that policies address needs specific to the national or local context;
- incorporate robust qualitative and quantitative evaluations into health literacy policies and interventions – quantitative methods could include pre- and post-activity health literacy evaluations of evidence of health, social and economic effects at all levels;
- incorporate facilitators of successful implementation, such as inter-sectoral working, political leadership and strategies to overcome cultural barriers, into health literacy policy.

1.5 Capacity building

Successfully addressing the challenges of limited health literacy as outlined in the abovementioned recommendations requires that the public health system and other actors involved in taking action to address health literacy have sufficient capacity to do so. The term “capacity building” is used to describe the conditions that must be present in order to achieve a target and to sustain it over time, independently of external events. In their report on the public health capacity throughout EU Member States³³, Aluttis, Van den Broucke, Chiotan et al. identified six core domains for public health capacity (see Figure 3): knowledge development; a competent workforce; organisational and institutional capacity; partnerships; leadership and governance; and financial resources. These capacities can be available at country- or regional level, and must be adapted to the country-specific context.

**Figure 3 – Conceptual framework for public health capacities³⁴**

Source: Reproduced from Aluttis et al (2014)



Applying this framework to Health Literacy, Van den Broucke (2019) describes these six dimensions as follows:²⁰

1.5.1 Knowledge development

The development of a strong knowledge base with regard to health literacy requires a research infrastructure at national and international level that allows for the systematic collection of relevant high-quality data regarding the health literacy of the population, the determinants and consequences of low health literacy, and the effects of interventions aimed at tackling low health literacy, with a view to inform evidence-based policies. Particularly relevant would be to set up **monitoring systems** to measure the evolution of population health literacy over time, and to **evaluate the effects of interventions** within and outside the healthcare setting to enhance health literacy or help low health-literate people access and navigate health services.

A key principle of capacity building is that it **builds on the existing capacities** of the system. Attempts to enhance public health capacities must therefore be based on an analysis of which capacities already exist, how well they are developed, and how well they link together as a system. This analysis is referred to as capacity mapping, and ideally involves a systematic assessment of existing capacities based on a predefined conceptual framework.

1.5.2 Workforce development

It goes without saying that a good healthcare system must rely on highly qualified professionals. Nowadays, healthcare workers must also be competent in terms of human relations and empathy, and are being trained for this as well. But this is still not enough to improve patients' health literacy. Health workers have to be able to **adapt their ways of communicating and interacting with people**. These skills and competences are quite new for many health care professionals; they necessitate awareness raising and specific training. Incidental or informal learning as well as formal learning strategies, dissemination of best practices, guidelines and tools are required in this respect. For the future professionals, health literacy awareness and skills training will have to be integrated in their basic training curriculum,

while paying attention to achieve consistency across institutions or disciplines.

Van den Broucke also advises that these skills should ideally be included in certification and accreditation systems; he gives the example of the Core Competencies Framework for Health Promotion (CompHP) developed by the International Union for Health Promotion and Education (IUHPE) which explicitly lists health literacy as a required core knowledge and skill for the professional health promotion specialist.

Box 1 – Health Literacy Universal Precautions³⁵

Because limited health literacy is common and is hard to recognize, experts recommend using health literacy universal precautions. Practices should assume that all patients and caregivers may have difficulty comprehending health information and should communicate in ways that anyone can understand. **Health literacy universal precautions** are aimed at:

- simplifying communication with and confirming comprehension for all patients, so that the risk of miscommunication is minimized;
- making the office environment and health care system easier to navigate;
- supporting patients' efforts to improve their health.

Everyone gains from health literacy universal precautions. Research shows that interventions designed for people with limited health literacy also benefit those with stronger health literacy skills. Communicating clearly helps people feel more involved in their health care and increases the chances of following through on their treatment plans. All patients appreciate receiving information that is clear and easy to act on.



1.5.3 Organisational and institutional capacity

“Organisational capacity refers to the degree to which structures, systems, procedures and practices of organisations within a community are in place to attain their mission and objectives, and that change is managed effectively.” (Van den Broucke, 2019²⁰ p 711). As defined by Brach and colleagues in the seminal paper of the US Institute of Medicine, an organisation can be considered as health-literate when it *‘makes it easier for people to navigate, understand, and use information and services to take care of their health’* (Brach et al, 2012, Ten Attributes of Health Literate Health Care Organizations³⁶ p 2). As such, the concept of organisational health literacy acknowledges that in addition to an individual’s abilities, the demands and complexities of health and social care systems are also vitally important.

Building the organisational capacity to address health literacy can involve interventions in various areas of organisational functioning: strategic planning (for example, introduce health literacy as a core element in the business plans of organisations in the health sector), management change (for example, involve senior managers in steering committees for projects dealing with health literacy), improving policies and procedures (for example, ensure the allocation of a budget to initiatives to enhance health literacy), introducing quality systems (for example, use quality guidelines and tools for actions to address low health literacy), reviewing recognition and reward systems (for example, incorporate attention for health literacy in job descriptions and reward employees who achieve well in this area), or changing the organisational culture (for example, encourage attitudes in support of health literacy).

Box 2 – The 10 attributes of a health-literate organisation (Brach et al 2012)³⁶

1. it has leadership that makes health literacy integral to its mission, structure and operations;
2. it integrates health literacy into planning, evaluation measures, service users’ safety and quality improvement;
3. it prepares the workforce to be health literate and monitors progress;
4. it includes populations served in the design, implementation and evaluation of health and related information and services;
5. it meets the needs of populations with a range of health literacy skills while avoiding stigmatisation;
6. it uses health literacy strategies in interpersonal communications, and confirms understanding at all points of contact;
7. it provides easy access to health and related information and services and navigation assistance;
8. it designs and distributes print, audio-visual and social media content that is easy to understand and act on;
9. it addresses health literacy in high-risk situations, including care transitions, communications about medicines, etc;
10. it communicates clearly what health plans cover and what services individuals will have to pay for.



Checklists to measure the presence of the ten attributes in a health or social care organisation have been developed. An example of such a checklist is Enliven's self-assessment resource.³⁷ Other authors have developed more complex models of health literate organisations, like for example the Vienna Concept of Organisational Health Literacy (V-HLO)^{38, 39} or the Organisational Health Literacy Responsiveness Assessment (Org-HLR).^{40, 41} V-HLO has a larger scope, in that it also addresses the fields of prevention, health promotion and public health, it has recently been translated and validated in French.⁴² These models and tools offer guidance for the quality improvement process that will help organisations enhance their capacity to address health literacy in a systematic way. These organisations do not have to be limited to the hospitals but they can be equally applied to organisations of any kind both within and outside the health sector.

1.5.4 Partnerships

Developing partnerships contributes to strengthening the public health system's capacity to address the health literacy challenge. Indeed, health literacy is not only a concern for the healthcare sector but also requires integrated action by civil society, politicians and the private sector. Collaboration should be fostered between organisations at local, national and international level in order to join forces. Interesting examples of partnerships at the national level are seen in the Netherlands and in Ireland (see further). Other partnerships operate at community level, where community members can collaborate to improve policies, programmes and practices related to health literacy.

However, the effectiveness of a partnership depends on the extent to which the participating organisations share common goals, mutual perspectives and resources, and are able to communicate effectively.

1.5.5 Financial and non-financial resources

When considering the capacity of a health system, the issue of resources is always a sensitive one. Simply put, the possibility to develop all other capacity domains often depends on the availability and allocation of resources. Resource allocation involves the decision-making processes that ensure that an appropriate mix of goods and (financial and non-financial) resources is made available to organisations in the sector or community, to maximise the chances of reaching the goals. Besides financial resources, human resources, information, administrative and physical resources must also be considered.

1.5.6 Governance and leadership

Governance for health promotes joint action of healthcare and non-healthcare sectors, of public and private actors and of citizens, and requires a synergistic set of policies, many of which reside in other sectors than the health sector (e.g. education) or even outside the government.

Leadership refers to the characteristics of people within an organisation or community to search opportunities for growth, to set examples, to inspire, mobilise and enable others to act, and to encourage them by recognising their contributions to success. Building leadership for health literacy requires the identification of champions who are able to mobilise actors and communities, encouraging their visioning and strategic thinking, and strengthening their personal, interpersonal, organisational and technical skills.



Box 3 – Education, an example of inter-sectoral governance goal for a health literacy action plan

A critical example of how health literacy can be promoted through governance action is education. Opportunities for teaching health literacy matters occur at all ages and at all levels of the educational system, from nursery to university. For instance, the German health literacy plan⁴³ (not analysed in this report) sets as very first recommendation “*Enable the education system to promote health literacy early in life*” and suggests to incorporate health literacy into the curricula of nurseries (they insist on the necessity to start at an early age), primary schools, secondary schools, universities, youth education and occupational training institutions as well as adult learning centres. The German Federal Ministry of Education sponsors a project of [Health Literate Schools](#) to adapt the attributes of the “Health Literate Organisation” concept (see Box 2) for the school settings.

In Finland, health literacy is now seen as a theoretical framework for the Health Education curriculum.⁴⁴ Argument for this is that health literacy is relevant for all (future) citizens and that its incorporation in the curriculum has the potential to guarantee that all school-aged children will be able to learn the competencies they need to take care of their own health and the health of others: “*Health literacy enables people to understand themselves, others and the world in a way that will enable them to make sound health decisions, and to work on and change the factors that constitute their own and others’ health chances.*” (Paakkari 2019 p 525⁴⁴) Health literacy has also been adopted into the school curriculum of the Czech Republic; in Australia, it is incorporated in the Health and Physical Education Curriculum.

Such an ambitious goal requires considerable synergies to be established between many levels of competence, and therefore demands a real willingness on the part of the authorities of a country.

2 MATERIALS AND METHOD

2.1 Goal of the study

This study was undertaken on request of the Belgian Federal Public Service of Health, Food Chain Safety and Environment. The aim of this research project is to learn from health literacy policies and action plans of other countries in order to make recommendations on elements and criteria to take into account for the development of an eventual Belgian national Health Literacy plan. We will use the general term ‘policy’ in reference to the definition of Buse et al (2012)⁴⁵ stating that health policies are courses of action and inaction that affect the sets of institutions, organizations, services and funding arrangements of the health system, and we will use the term ‘action plan’ when we refer to a coherent plan specifically dedicated to the improvement of health literacy, most often set up as such by the authorities (see 4.2.1).

2.2 Design of the study

For this study, a three-pronged approach was followed: (1) identification of Health Literacy policies and initiatives in Belgium, (2) a transversal analysis of Health Literacy policies in a 6 foreign countries, and (3) assessment of feasibility and applicability in Belgium of the identified foreign policy approaches in a group of Belgian stakeholders.

2.3 Identification of Health Literacy policies and initiatives in Belgium

A search for information in the scientific and grey literature was conducted to identify Health Literacy initiatives and policies in Belgium between 15/04/19 and 30/06/19.

First, the databases Medline and Cinahl were searched by means of the terms “Policy”[Mesh]), “Health Literacy”[Mesh] and “Belgium”. Subsequently, a Google search was set up to identify Belgian initiatives by means of Dutch, French and English Health Literacy-related search terms and snowballing. Third, a final search was conducted on the websites of the



major governmental federal and federated healthcare institutions and Belgian legislative/governmental websites. Fourth, in case of uncertainty about certain aspects, organisations were contacted to clarify.

2.4 Transversal analysis of foreign Health Literacy policies

An in-depth analysis of Health Literacy policies in six countries was conducted.

2.4.1 Choice of the countries

The countries for this transversal analysis were selected by means of a preliminary scoping review on the availability of publications and information regarding regional or federal Health Literacy policies. This yielded a provisional list of countries, which was then discussed in depth with a Belgian expert on Health Literacy. Criteria taken into account were, (amongst others): the organisation of healthcare, the state structure (e.g. federal and regional policy levels), and the availability of best practices. This resulted in a reduction of the longlist to 6 countries:

- **Australia (AUS)** is very active in research on health literacy but also is a federal country like Belgium;
- **Austria (AT)** has heavily invested in health literacy after the publication of the results of the HLS-EU study and has reached very good results in a short time. Moreover, it is also a federal country;
- **Ireland (IE)** has a health literacy policy that has the characteristic of being mainly driven by the associative sector;
- **The Netherlands (NED)** despite the absence of a specific governmental health literacy policy or action plan, the population has very high levels of health literacy;
- **Portugal (POR)** has recently invested much energy in enhancing health literacy in the population, after a survey showing that Portuguese scored low on health literacy compared to other European countries;

- **Scotland (SCOT)** is a nation within a federation of states that has a very interesting health literacy action plan that appears to be very successful.

For all of these countries, local experts were identified and contacted for interviews. The list of names is to be found in the colophon (external experts).

2.4.2 Development of the analytical grid

The analytical grid, to collect and structure information from the six selected countries was created on the basis of two key publications: The Health Evidence Network Synthesis Report N° 57 based on a study by Rowlands et al (2018) for WHO-EU³² and an article by Cheung et al (2010) on a tool to compare, analyse and evaluate policy documents.⁴⁶ Relevant elements described in these papers were gathered in an information grid and refined and adapted to the Belgian situation (e.g. adding items about the relation between central state and regions for federal states), in a workshop with project members. The final information grid was validated by a Belgian expert on Health Literacy.

2.4.3 Data collection method

In order to describe the Health Literacy policies of the selected countries, we first searched in scientific and grey literature in bibliographic databases, on internet search engines and on governmental websites. Secondly we contacted local experts with large experience in the field of Health Literacy policies (generally directly involved in the implementation of the action plan) to validate the information gathered and to complete it. A transversal comparison was then performed on all six country grids. Each topic was analysed separately.



2.5 Formulation of recommendations for a Belgian action plan

The results of the transversal analysis of foreign health literacy policies were translated into recommendations for a Belgian action plan. These recommendations were presented in a Powerpoint to an audience of 16 Belgian stakeholders during a meeting on Nov 5th, 2019. The invited stakeholders were representatives of the Health administration (federal and Communities), the health insurance funds, the health promotion associations, the patients' and consumers' organisations and the King Baudouin Foundation. It was an open and frank, not structured discussion, that allowed to enrich and refine the final recommendations without altering their essence.

3 HEALTH LITERACY IN BELGIUM

As a matter of fact, Belgium is rather late on the way to Health Literacy. The concept is designated under different names, as 'gezondheidswijsheid', 'gezondheidsgeletterdheid' in Dutch, 'litteracie en santé' or 'éducation pour la santé' (but the latter is wider as concept) in French.

3.1 The level of Health Literacy in Belgium

Belgium did not take part in the HLS-EU study (see 1.2), the results of which were published in 2015.¹⁷ Therefore, we have no possibility to directly compare our country to other European countries on this basis. A new population study of health literacy is planned for the near future, by the M-POHL Network under auspices of WHO Europe's Health Information Initiative (EHII) (<https://m-pohl.net/>). This new survey will gather data from 20 countries, including Belgium (see further).

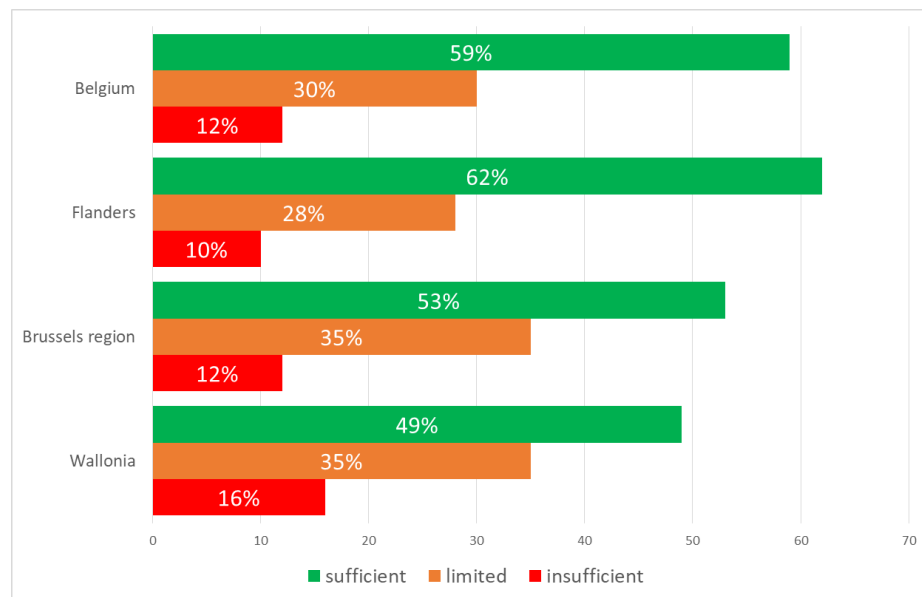
3.1.1 2014 – Study of the Christian Health Insurance Fund

However, an online study of the level of health literacy in a sample of 9616 respondents was conducted in 2014 in Belgium by the Christian Health Insurance Fund (CM-MC), in collaboration with the UCL.⁴⁷ This study used the short form of the questionnaire applied in the HLS-EU study, and also collected information about the social status of the respondents (education, work status, health behaviour, use of non-reimbursed medication...).

The results of this survey showed that health literacy is "limited" for three Belgians out of ten (29.7%) and "insufficient" for a little more than one out of ten (11.6%). This means that in total, four out of ten Belgians have limited capacities to lead a healthy life, and don't have the skills to improve their situation. These scores are in the same range as those of the majority of the other European countries, but are far below the performance of our neighbours in the Netherlands.



Figure 4 – Levels of health literacy according to the region in Belgium



Source : Vancorenland et al, 2014⁴⁷

Flanders had the highest percentage of adequate health literacy (61.9%), followed by Brussels (52.5%) and Wallonia (48.7%). Gender and age affected health literacy skills: the percentage of sufficient literacy was significantly higher among women (60.9%) than men (56.2%). It was also better in subjects aged 25 to 74 years (approx. 60%) than in young adults in the 18-24 age group (45.5%) and in those over 75 years of age (49.2%).

The differences in health literacy were particularly marked according to the educational level. In people with lower education, 39% had limited health literacy skills and 19% had an inadequate level. In people with a higher education, this was respectively 22% and 4%. Each rise in level of education corresponded to an increase in health literacy.

The researchers also investigated whether an adequate level of health literacy was related to making the right choices for health behaviour. They found a significant positive relationship with healthy nutrition, physical exercise and medication use. Finally, the authors argued for investment in health literacy and improving access to healthcare information for people with low(er) levels of health literacy.

3.1.2 2018 – Sciensano National Health Survey

The latest Health Interview Survey (HIS 2018) included a short (6 items) measure of health literacy based on the questionnaire used in the HLS-EU survey (HLS-EU-Q6). The 6 items are reproduced in Figure 5. This short form has been validated on the HLS-EU sample and a French translation has been validated on a sample of the French population.⁴⁸

**Figure 5 – Questions related to health literacy in the Health Survey 2018**

HL.01 How easy or difficult is it for you to: (one tick per line)	Very easy	Rather easy	Rather difficult	Very difficult
01. to assess when you may need to seek a second medical opinion (from another doctor)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
02. using the information the doctor gives you to make a decision about an illness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
03. to find information about how you can deal with certain psychological problems such as stress or depression?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
04. to assess whether the information about health risks in the media (TV, internet, others) is reliable?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
05. to find information about activities that are good for your psychological well-being (e.g. meditation, sports, walking, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
06. to understand information in the media (TV, internet, others) about how you can become healthier?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The results can be summarised as follows⁴⁹:

- In 2018, 66.6% of people aged 15 and over had a sufficient level of HL, 27.8% a limited level and 5.6% an insufficient level. Thus, overall, one third (33.4%) of the Belgians aged 15 and over have a low level of HL, and as such have limited capacities to access, understand, appraise and /or apply information about health.
- Men were more likely to have a sufficient level of HL than women: 68.3% of men compared to 65.0% of women had a sufficient level.
- People aged 75 and over were significantly less likely to have a sufficient level of HL (54.5%) compared to younger age groups (rates ranging from 63.0% to 72.5% for those aged 25-74).
- The level of HL increased significantly with the education level: 71.7% of people with a higher education diploma had a sufficient level of HL, 65.2% of those with a high school diploma, 55.4% of those with a lower secondary diploma, and 43.2% of those with a primary diploma or no diploma.

- The percentage of people with a sufficient level of HL was higher in Flanders (69.3%) than in the other two Regions (63.2% in Brussels and 62.7% in Wallonia).
- The level of HL increased with improved health status: people reporting subjective ill health and those reporting two or more chronic diseases were less likely to have adequate literacy levels.

These results globally confirm the results of the study of Vancorenland et al. (see 3.1.1) but some differences are observed, namely the better score of men compared to women and the general level of sufficient HL that is slightly better in the Health Survey. Authors point out differences in the version of the HLS-EU questionnaire (6 items here and 16 in the CM/MC study) and the sample (national sample versus members of a health insurance fund). Nevertheless, even if the results are 'better' in 2018, they conclude that the level of HL in Belgium remains insufficient.⁴⁹

3.1.3 Other studies from the Health Insurance Funds

In 2016, the health insurance fund Mutualités Libres-Onafhankelijke Ziekenfonds financed a survey about the quality of communication between physicians and patients, among 1033 adult civilians.^{50,51} The results showed that 40% of them had problems in understanding what the doctor said, of which 17% even found it very difficult. Patients with difficulties in understanding their physician also had higher odds for forgetting their prescribed medication, not attending additional prescribed medical investigation visits, not attending follow-up consultations with their GP and having a less healthy lifestyle (sports, eating habits, ...). Therapy adherence was significantly lower in this group. The study also showed that 32% of the respondents had problems understanding medication leaflets.

In another survey published in 2017 about « Health information in French-speaking Belgium »⁵², the Solidaris Institute (linked to the Socialist health insurance fund) confirmed that the level of health literacy in Belgium was not optimal but also noted that especially the ability to access high quality information and the evaluation of health information were the most problematic issues. The results of this survey showed that many people do not understand and take ownership of health information. However, this seemed to be facilitated when information was issued by a health



professional. The study concluded that the health professionals are privileged interlocutors in the delivery and / or discussing of health information. It also recommended working on people's psychosocial skills (motivation and self-esteem) and not only on the quality of information.

3.2 Current Health Literacy policy in Belgium

In 2014, the HEALIT4EU project stated that the concept of health literacy was not very well known in Belgium (the term is known but not currently used) and that health literacy was neither implemented in national policies in Belgium, nor were there concrete plans or policy intentions related to health literacy for the future. Sparse information was found that the Flemish minister of well-being indicated his plans to integrate health literacy education strategies in his policy. However, this snapshot of the Belgian situation in 2014 was exclusively focused on research projects; this explains why it did not quite reflect the actual situation and did not account for the evolution that was taking place. An awareness has gradually developed both on the field and at the policy level about the need to focus on the topic. In recent years, several milestones have been set at the political and institutional level.

3.2.1 Health in all policies – Charter in Flanders (2003)

The decree of the Flemish Government of 21 November 2003 took into account a "Health in All Policies" approach (HiAP), more specifically with a focus on health promotion and prevention.^{53, 54} Among others, attention to health literacy, social inclusion of vulnerable groups and digitalisation as a social phenomenon were taken into account. In that context, all policy plans of the Flemish Government and the Vision Statement 2050 (a long term strategy for Flanders) were screened for common grounds with health promotion and prevention. Besides, a dialogue with the Federal policy level regarding these topics was initiated.

3.2.2 Recommendations on Health Literacy from the (Flemish) Royal Academy of Medicine (Koninklijke Academie voor Geneeskunde van België -KAGB) (2014)

In 2014, the KAGB made the following recommendations for the policy makers:

The policymakers have to take initiatives to

- Follow up health literacy in the Belgian population;
- Integrate health literacy in healthcare, education, social care and media;
- React against desinformation or inappropriate healthcare claims;
- Provide financial incentives to people with low health literacy skills;
- Stimulate training of health care professionals in detection of and intervention for health literacy;
- Integrate initiatives for health literacy of clients, patients and care providers in quality assurance norms for healthcare institutions.

Policymakers were also asked to set up a platform or forum where interventions could be developed and fine-tuned and where good practices could be shared. The need for good population assessment instruments for health literacy was also emphasised. It was advised to identify existing good practices in Belgium and abroad and to initiate close collaboration with these expert partners with a view to re-enforce Belgian initiatives.

3.2.3 RIZIV – INAMI White paper (2014)

In the context of the 50th anniversary of the National Institute for Health and Disability Insurance (RIZIV – INAMI), around 30 actors from the health and social sectors (health insurance funds, patients, healthcare professionals, etc.) participated in the preparation of a Green Book, with an inventory of points of attention and improvement regarding access to healthcare. Based on this Green Book, a White Paper⁵⁵ was compiled with solutions for 5 priorities regarding access to healthcare.



The fifth point to work on, was “Creating new professions in the ambulatory sector (intercultural mediators, experiential experts) to improve the information ('health literacy') and the knowledge of the patient, and thus to strengthen his independence and decision-making capacity in the health system ('empowerment')”. The following actions need to be taken:

- Increasing the experience of intercultural mediators in primary care (a smooth and easily accessible system of support)
- Involvement of experiential experts in healthcare to support and empower people in their care trajectory.

RIZIV – INAMI states that appropriate training will have to be provided for the development of these new professions or roles. An agreement within the Inter-ministerial Conference with the federated entities must be given on the content of those courses.

3.2.4 *Mention in the federal coalition agreement of 9 October 2014*

A paragraph on increasing health literacy was included in the federal coalition agreement of 9 October 2014 stating that: “Initiatives that promote self-care and self-management are encouraged. Particular attention will be paid to promoting health literacy among the population, to better training of caregivers with regard to stimulating self-care and self-management, and to making accessible information available to the patient. The patient must have information about the quality and price of the care, which is made available through one accessible platform.”

In her policy note, the Minister of Health Maggie De Block added: “*I intend to continue working with the health insurance funds to develop a common multiannual framework in which several themes of the government agreement but also the expectations of the funds themselves can be addressed. On the agenda is an update of their current package of tasks, including increased service delivery, with an advisory role in members' efforts to maintain and/or recover their health. A move towards a health fund rather than a sickness fund.*” (De Block, 2015, section 11.1⁵⁶)

3.2.5 *FPS Public Health management agreement 2016 – 2018*

The management agreement FPS Health, Food chain safety and Environment 2016 – 2018 pays attention to health literacy. In the Operational Goal DGGS 9, focusing on the protection of health of the population in both life-threatening and non-life-threatening situations, it is stated that investment is needed to increase health literacy skills in the general population. One of the objectives is to setup a study regarding health literacy and another objective is development of a training program for healthcare professionals to stimulate self-management and self-care in patients and carers.

3.2.6 *The Flemish Charter of the rights of the patient/client (SAR-WGG) (2017)*

The Flemish Charter of the rights of the patient/client of 2017⁵⁷ is an operationalisation of the Flemish policy agreement of 23 July 2014. The Charter contains both individual and collective patient rights. Individual (human) rights serve to protect and develop the individual person in relation to his environment. One of these rights, the comprehensibility of healthcare information (i.e. article 3 and 4), emphasizes the duty to provide low threshold information to every patient and to make sure that the patient understands his condition and his options related to healthcare.

3.2.7 *Advice of the Flemish Strategical Advisory Board Well-being Health Family (SAR-WGG) (2017)*

This report is a proposal for Flemish Healthcare priorities to close (or reduce) social inequality in health and well-being. The report focuses on inequality in different socio-economical groups in Flanders. One of the levers to improve health outcomes in vulnerable groups is to improve their health literacy. Investments in health literacy (and more specifically in mental health literacy) is crucial as it results in faster and more adequate access to healthcare. The SAR-WGG pleads for involvement of policy makers to align and structure activities of “LOGO's, Huizen van het Kind, CAW, OCMW, Ziekefondsen, gemeenten, verenigingen, *eerstelijnszorgverleners en de lokale gemeenschap*”. All of these partners need to improve accessibility and comprehensibility and decrease complexity of the healthcare system.



One must take into account individual differences in health literacy and needs for information, support and coaching. Finally, SAR-WGG emphasizes the importance of the educational system (starting from primary education) to establish good levels of health literacy in the population.

3.2.8 Motion for a resolution to introduce an Action Plan to significantly improve the Health Literacy of Belgians (2018)

On April 19, 2018, the deputies Ine Somers (Open VLD), Damien Thiéry (MR) and Jan Vercammen (NVA) have submitted a motion for a resolution to introduce an action plan to significantly improve the health literacy of the Belgians.⁵⁸ This document was discussed in May 29, 2018.

The motion states:

- That there is a need for nationally measuring health literacy in the Belgian population as in Belgium no official data are available regarding this topic;
- That it is desirable to consult with the communities so that the federal government and the communities each pursue the same goals with their actions;
- That it is essential to pay particular attention to the target groups where health literacy is lowest, as there is increasing evidence that the lack of health literacy is directly related to health inequalities;
- That it is necessary to set up a health literacy working group with all the actors involved (health care providers, health insurance funds, etc.) to participate in setting up the national strategy, implementation to monitor and evaluate and, if necessary, formulate proposals for adjustment with the aim of achieving the health objective. Ideally, the communities and regions should also be involved;
- That it is essential to raise awareness among care providers and to convince them through education, good practices and other actions of the importance of health literacy for a better compliance and lifestyle adjustment. The importance of health literacy is especially relevant in the context of self-management of chronic patients. Training is needed to develop better communication skills and techniques among

healthcare professionals to assess whether provision of information results in understanding in patients;

- That it is desirable to invest in the improvement of health literacy;
- That it is necessary to investigate whether written information can be replaced by other forms of information (e.g. pictograms, infographics, social media, ...);
- That it is necessary to tailor interventions to the specific needs of patient (groups);
- That Health Literacy must be a national healthcare priority and
- That there is a need for a national Health Literacy Plan including a health literacy index and national mapping of health literacy. Health literacy improvement efforts must be evaluated for effectivity based on this index.

3.2.9 The strategic plan for health promotion 2018/2022 of the French-speaking government of Brussels.

As stated in the 2016 health promotion decree of the Commission Communautaire Française de la Région Bruxelles-Capitale (COCOF)⁵⁹ a strategic plan for health promotion had to be developed. This was done for the time frame 2018-2022.⁶⁰ One of the aims of the first priority ("to promote the visibility, accessibility and ownership of health promotion information and resources") was (1) to support the development of health literacy, (2) to ensure the reception, understanding and appropriation of tools and products in health promotion by the target audiences, and (3) to pay particular attention to the reduction of social inequalities of health and to the public in situation of migration. To meet these goals it was decided to set up a call for candidates (experts, academics) to support health literacy actors. It was also decided to organise an inter-ministerial negotiation platform to define and implement with Wallonia and the Fédération Wallonie-Bruxelles (FWB) a system for the provision of free radio and television spaces for health promotion campaigns.



3.3 Existing initiatives on the field

Notwithstanding the fact that there is no real public investment in health literacy in Belgium, many actors are engaged in different projects.

3.3.1 *Heerlijk Helder in de Zorg (expertisecentrum MEMORI, Thomas More, 2016)*

The expertise centre of MEMORI (Thomas More University College) focuses on health literacy (education, training and intervention). It has set up a study- and development project 'Heerlijk Helder in de Zorg' that resulted in 7 small books for health care professionals (in Dutch only: <http://www.memori.be/heerlijk-helder-in-de-zorg.html>). These booklets offer an answer on the following questions:

- How can healthcare professionals recognize low health literacy skills in patients or clients?
- To what extent are counter talks, telephone talks and care talks low threshold?
- How easy finds a patient the right track in your health environment?
- How accessible are your printed information materials?
- What are the recommendations to make oral or printed communications more understandable for patients?
- What are the alternatives for medical 'jargon'?
- How do you sensitize care providers about health literacy issues?
- How do you create a support for an improvement trajectory?
- How do you approach such an improvement process in a practical way?

The toolkit contains recognition pointers, guides, checklists and accessibility measures that can help hospitals and other healthcare environments to make employees aware of the issue of low health skills and that enable improvement projects towards accessible communication.

3.3.2 *Littératie en santé (Culture & Santé ASBL, Octobre 2016)*

Culture & Santé (<https://www.cultures-sante.be/>) is a not-for-profit organisation in Brussels concerned with health promotion, lifelong learning and social cohesion, with expertise in communication adapted to multicultural and/or poorly educated audiences. The organisation has compiled a list of information and literature sources (in French only) that contains information about concepts and terminology, statistical publications, thematic reports, information regarding accessibility to information, references concerning specific groups with specific needs, information regarding digital health literacy, a list of actions and projects in Belgium; a list of guides to undertake action and a number of pedagogic tools and aids. The organisation also offers trainings and information sessions for intermediaries in order to train these people in the application of the different tools in specific populations (e.g. Training focused on improvement of health literacy in migrants).

Culture & Santé is supported by several governmental organisations (e.g. AViQ, Fédération Wallonie-Bruxelles, Actiris). In 2017 this organisation won the MSD Well Done Community Award for Health Literacy.

3.3.3 *Oog voor gezondheidsvaardigheden (VIGEZ, 2016)*

The Flemish Institute for healthy living (VIGEZ) published a booklet⁶¹ on health literacy aimed at healthcare practitioners (in Dutch only). The booklet emphasizes that addressing the health literacy challenge is a complex matter because, besides 'real' health literacy, communication, interaction, language, and social skills are also needed to process healthcare information. Therefore both the individual person and his/her context, need to be taken into account. Multi-layer, multi-faceted interventions must be set up to improve health literacy. To that effect, it is important to first recognize the level of health literacy in patients. Secondly, a tailored communication is needed providing information in both oral and printed format. One must be aware that there are several 'sub-groups' in the population that need an adapted approach or even other end-points and goals. Improving health literacy should be a goal of every healthcare organisation and must be embedded in the mission, the structure and the activities of the organisation. Training and education is needed for all healthcare professionals.



3.3.4 *The Well Done MSD Health Literacy Awards (until 2017) and MSD HealthNest (from 2018)*

Since 2013, the pharmaceutical company MSD organizes the “Well Done MSD Health Literacy Awards”, to encourage, reward and raise awareness of the best health literacy initiatives in Belgium. The long-term ambition of this initiative is to emphasize the importance and impact of health literacy and to optimize it in order to improve health care in Belgium.

MSD organises this contest in collaboration with several scientific organisations, including SSMG & Domus Medica for the general practitioners, APB for the pharmacists, AUVB/UGIB for the nurses; the RIZIV – INAMI, the main health insurance funds (CM/MC, Onafhankelijke Ziekenfondsen/Mutualités Libres and Socialistische mutualiteiten/Mutualités socialistes), the Belgian Cardiological Association, the Foundation against cancer, a physician syndicate BVAS/ABSYM, an association of cooperative pharmacies (Ophaco) and a media specialised in healthcare communication (Reflexion Medical Network).

The call is open for every group or person with interest in health literacy. An independent jury (healthcare professionals and HL experts) evaluates the proposals submitted. The evaluation criteria rely on the relevance, feasibility, innovative aspects, evidence-based evaluation and multiplicability of the submitted projects.

Over a period of 5 years, approximately 200 projects have been submitted. There are three types of awards: one for primary care (open for GPs, home nurses, pharmacists, physiotherapists...), one for specialized care (open for medical specialists, midwives, catering managers in hospitals, physiotherapists in hospitals...) and one for communities (open for public organisations, patient representative organisations, private persons...).

In 2018 MSD launched the HealthNest initiative, as the successor of the WellDone Awards (<https://www.healthnest.be>). This initiative, with the same partners as the Well Done Awards plus Zorgnet Vlaanderen-Icuro and Gezondheid & Wetenschap, aims to identify the best projects on health literacy in Belgium and act as an incubator for implementation of these projects.

3.3.5 *Gezondheid en Wetenschap*

A few years ago, the Flemish government funded a health literacy project related to the Evidence-based practice (EBP) projects in Belgium. Since more than 10 years the Federal Government provides about 1000 EBP-guidelines for professionals. As the EBP concept is a combination of (1) the expertise of the professional, (2) the best evidence available, and (3) a well-informed patient, there was a need to provide clear and correct ‘layman’ EBP information for patients and caregivers. Based on the Federal EBP-guidelines in the Ebpracticenet portal, patient guidelines have been developed and made available through a patient internet portal (www.gezondheidenwetenschap.be). At present about 950 patient guidelines are available. All of these have a direct link with the Ebpracticenet content. The content of the layman-portal is validated by CEBAM (Center of Evidence-Based Medicine in Belgium).

As an incentive, to attract civilians to the website, a daily news fact regarding healthcare is critically appraised and a short layman text is provided to confirm, deny or amend the news fact. At present, the Gezondheidenwetenschap-portal is quite successful. The portal is funded by the Flemish Government and was only available in Dutch until recently. An agreement was concluded with the Department of General Medicine of ULiège, and the site is now also available in French (<https://www.infosante.be/>).

Gezondheid en Wetenschap is also partner of the MSD HealthNest initiative.

3.3.6 *Mon Généraliste.be*

Similar to the Gezondheidenwetenschap-portal, there is also an initiative in the French speaking part of Belgium: www.mongeneraliste.be.

This website, created by the GP organisation SSMG, provides approximately 130 patient guidelines, to inform lay public about diseases. Negotiations between SSMG and Gezondheid en Wetenschap are ongoing in order to collaborate.

Mongénéraliste.be gets support from the two main health insurance funds (Mutualités chrétiennes and Solidaris) as well as from the French-speaking health authorities (AViQ, Fédération Wallonie-Bruxelles).



3.3.7 *MondocMasanté / MijnthuisdokterMijngezondheid*

[MondocMasanté / MijnthuisdokterMijngezondheid](#) is a bilingual web-platform that aims to improve communication between the patient and the general practitioner and to increase the knowledge of the patient about his health and his diseases. The visual information (schemas, simple texts, videos ...) it contains can be used by the physicians during the consultation and can also be retrieved by the patient at home. This project is financed by Innoviris, the Brussels Institute for Scientific Research and Innovation, with contributions from the pharmaceutical sector (Servier and Biocodex) and in collaboration with health associations (Diabetes association, Asthma, Foundation against cancer) and health media.

3.3.8 *The Dr Daniël De Coninck Fund steered by the King Baudouin Foundation (2018)*

The Dr. Daniël De Coninck Fund⁶², managed by the King Baudouin Foundation, invests in high-quality primary care since 2018. The main aim of this fund is to increase health literacy of civilians in Belgium in order to empower these people to take up the role of shared-decision maker for their health related issues. The Fund follows three tracks: supporting projects that directly contribute to the quality of life of patients in home care, supporting primary care professionals and building up knowledge about primary care.

- To encourage vision development, research and innovation in primary care, the Fund finances two interdisciplinary chairs, one in Flanders and one in Wallonia-Brussels. These chairs, with a strong focus on cooperation between universities and university colleges, must stimulate knowledge acquisition and knowledge sharing on primary care in Belgium.
- In 2018, a research project consisting of selecting and examining ten innovative international “best practices” that strengthen the health literacy of citizens, patients, caregivers and professionals was conducted. This initiative seeks to open a dialogue with communities, regions and the federal government on the political lever that health literacy represents to promote public health and social equality. The results of this mission are highlighted in a publication aiming at inspiring (Belgian) organisations in their initiatives to improve health literacy in

their field of action. Subsequently, a call for projects was launched at the end of 2018 and 25 projects were retrieved (12 French-speaking and 13 Dutch-speaking). These projects will receive a total amount of 867.251 € and will benefit from interventions and exchange of knowledge.

3.3.9 *The health insurance funds*

The health insurance funds play an important role in advising patients and citizens to maintain and/or recover their health. The policy brief of the Minister of Health in 2015 has initiated an evolution in the conception of their role, from ‘intermediary for payment to Health Coach’. All Health Insurance Funds in Belgium mention HL as a permanent and important part of their work. Their interventions are more or less similar and can be summarised following 3 types of actions:

- Issuing information about health, health promotion and healthcare that is easy to find and understand for all types of public (or for specific target populations);
- Empowerment of their members (clients) by offering health education activities, lifelong education, trainings, workshops, etc.;
- Simplification of their own administrative systems, awareness raising and training of their staff, advocating at federal level for a more user-friendly health system (e.g.: automation of access to rights). (NB: improving accessibility to care does not necessarily enhance the health literacy of the public).

A (non-exhaustive) overview of policies and activities of the health insurance funds can be found in the supplement of this report.



3.3.10 Efforts of the Belgian patient representative platforms

From their establishment, Vlaams Patientenplatform (VPP)⁶³, Ligue des Usagers des Services de Santé (LUSS)⁶⁴ and Patient Rat & Treff (PRT)⁶⁵ have invested considerable time and resources in lobbying for the patients' rights and provision of low threshold healthcare-related information (website, publications, and exchange events). Their aim is to empower the patient to be an informed and equal partner in decision making for his/her health and healthcare.

3.3.11 Test Gezond / Test Santé

Test-Aankoop/Test-Achats aims to provide objective and clear information regarding a broad scope of topics to its members, also concerning health and healthcare issues. For that purpose a specific publication, Test Gezond / Test Santé⁶⁶, is published seven times a year since 1995. Every journal covers a number of health(care) related topics, written with a critical eye in low threshold language at the level of the citizen.

3.3.12 The communities and the civil society

Finally, it must be highlighted that many organisations – not to forget the media – contribute to health literacy by providing 'layman' health information to the general public and by engaging in numerous health promotion activities. However they do not necessarily use the term 'health literacy'. The fact that more and more of these initiatives have been submitted to the call for projects of the Dr Daniël de Coninck Fund (see 3.3.8) and of the Health Literacy Awards / HealthNest initiative (see 3.3.4) is a sign that the concept of Health Literacy is gaining visibility. An exhaustive inventory of this wealth of actions was out of scope of this research.

4 INTERNATIONAL COMPARISON

For the purpose of this report, the policy statements and action plans about Health Literacy of six countries were studied: Australia (AUS), Austria (AT), Ireland (IE), the Netherlands (NL), Portugal (POR) and Scotland (SCOT).

Some of these countries have launched full-fledged, standalone, health literacy action plans (AUS, POR, SCOT) that are published and supported as such by the authorities, while others have a broader action plan covering the whole health and care sector and encompassing some points relating to HL (AT, IE, NL). Ireland has both but only the national plan is supported by the authorities. The Table 1 summarises the two types of action plans.

Table 1 – Scope of the studied HL action plans

Standalone HL action plan	General health plan
<ul style="list-style-type: none"> • SCOTLAND: two successive HL action plans have been put in place by the Scottish authorities: Make it easy (2014)⁶⁷ and Make it easier (2017).⁶⁸ • PORTUGAL: a specific HL Action Plan was launched in 2018: Plano de Ação para a Literacia em Saúde⁶⁹ • AUSTRALIA: a « national statement » was published in 2014 in order to promote a coordinated and collaborative approach to systematically address HL nationally.⁷⁰ It was accompanied by a Background Paper.⁷¹ • IRELAND: Strategic plan for HL 2007-2010 published by the (NGO) National Adult Literacy Agency (NALA). Its aim was to connect health literacy issues to ongoing efforts to improve the competence and standards of healthcare settings being driven by the Health Information Quality Authority (HIQA). 	<ul style="list-style-type: none"> • AUSTRIA: the Austrian Federal Government's Health Plan consists of a list of 10 targets that must be achieved by 2032. Target number 3 is entirely devoted to improving HL. In parallel, HL actions are embedded in the ongoing Healthcare sector reform.⁷² • NETHERLANDS: one part of the national program for prevention 'Alles is Gezondheid (2014-2017, 2017-2021) is devoted to the amelioration of literacy in general. • IRELAND: In 2013, the health plan <i>Healthy Ireland</i> devoted one of its actions (Action 45) to the development of HL.⁷³



4.1 Background of the HL plans

4.1.1 Low levels of HL

Most of the European policies studied were initiated **after the publication of the results of the European Health Literacy Survey (EU-HLS)** – or of results from national measurements using the same methodology. The HLS-EU (2009-2012) found that an average of 47% of the citizens in the 8 participating countries had limited health literacy (with the exception of the Netherlands) (see Table 2). These low results ‘came as a shock’ in several countries, but it might be worth mentioning that – at least in Austria – they were also supported by *“a heavy national marketing related to a lack of public funding for the national study and a resulting co-funding by a pharmaceutical company that had a strong interest in supporting broad public debate and establishing contact with political decision-makers”* (Nowak, 2019, p. 454⁷⁴).

In **Australia**, awareness of the concept of HL among policy-makers dates back to the 1990s, when HL was added to Australia’s first set of national health goals and targets.⁷⁵ The first survey on Adult Literacy and Life Skills Survey was conducted in 2006 by the Australian Bureau of Statistics (ABS) to measure the literacy of adults aged 15–74 years, including their health literacy. Results were released in 2008 revealing that almost 60 % of Australian adults lacked sufficient functional HL to meet routine health demands (Australian Bureau of Statistics, 2009) (Anonymous, 2009)

Table 2 gives an overview of the levels of health literacy in the studied countries.

Table 2 – Overview of the HL levels of the studied countries

Country	Inadequate HL	Problematic HL	Sufficient HL	Excellent HL
Australia	19%	40%	41%	
Austria	18.2%	38.2%	33.7%	9.9%
Ireland	10.3%	29.7%	38.7%	21.3%
Netherlands	1.8%	26.9%	46.3%	25.1%
Portugal	10.9%	38.1%	42.2%	8.6%
Scotland	There is no survey over Health Literacy for Scotland, but a survey on general literacy in 2010 showed that 26.7% of the people had occasional difficulties with day-to-day reading and numeracy, and that 3.6% had severe constraints.			

Sources: *Australia*: Australian Bureau of Statistics (ABS) (Anonymous, 2009); *Austria, Ireland and Netherlands*: HLS-EU¹⁷; *Portugal*: HLS-PT⁷⁶; *Scotland*:⁷⁷

According to some authors, the remarkable results of the **Netherlands** in comparison with the rest of the European countries probably reflect the strong investment they made in health education and promotion over several decades, with specific master programs training professional health educators, leading research centres, and a well-staffed network of regional health centres tasked with health education. If we assume that HL is an effect indicator of health education, the investments made in health education in the past were successful in enhancing the health literacy of the Dutch population.



Box 4 – Why do the Netherlands score so high on Health Literacy?

Many authors wonder why the results of the HLS-EU study showed such a difference between the Netherlands and the other European countries. Several hypothesis have been evoked.

It is well known that the Netherlands have a very strong tradition of health education and health promotion. They have been pioneers in Europe in setting up the first university masters on the topic, and in creating a national centre for health education (Landelijk Centrum voor Gezondheidsvoorlichting en Opvoeding) in the years 1980, then the NIGZ (until 2012), as well as several health promotion institutes with each its own field of expertise. In this country, the profession of health educator is also much better developed than in Belgium; these professionals work at the community level on health determinants.

According to Kickbush et al, the strength of the Netherlands in health literacy is the result of a combination of efforts for empowerment of individuals or communities with improvement of health sector communication. These authors also point out a strong lobby for patients' rights, with one of the first legislations on informed consent, which obliges healthcare professionals to provide proper understandable information and to get the patient's approval before treatment.²³

At the institutional level – such as hospitals – patient councils negotiate with management for patient-friendly measures. Specialised communication experts work closely with people with limited literacy to develop smart solutions like pre-packaged medication, phone text messages with appointment reminders and interactive web sites.²³

Aluttis also underlines that there is a strong responsibility for public health, prevention and health promotion at the level of the municipalities, which have to formulate public health strategies for their area every four years.³³

There is also a decades-long tradition of health communication for migrants and minority groups, often in foreign languages, using information materials and involving mediators, interpreters and trainers.²³ All in all, the concern for health is deeply rooted throughout the whole Dutch society (workplaces, schools...), what can be seen as a high level of capacity building for health literacy.³³

Critics oppose the view that the Netherlands are also known for their very liberal policy, particularly in terms of health care coverage, with a high degree of individual responsibility. Reaching a high level of HL allows to consider the population more "capable" and therefore more individually responsible for their own health.

Healthcare system reforms

As already mentioned, some HL action plans take place within (or in parallel to) a **reform of the healthcare system** of the country, or at least on the occasion of some deep changes in the healthcare system. This is the case for Australia, Austria, Portugal and Scotland.

The **Australian** programme of health reform has been under way since 2010. It aims to improve the effectiveness, efficiency, appropriateness and accessibility of healthcare. Work is occurring in eight key streams: hospitals, general practice and primary health care, aged care, mental health, national standards and performance, workforce, prevention and e-health.(Health, Ageing, Health, & Staff, 2011) The Australian HL action plan was explicitly included in the (second edition of the) [national standards and performance stream](#)(Australian Commission on Safety and Quality in Health Care, 2012) as a criterion within the Partnering with Consumers Standard. These standards mandate the performance requirements of healthcare services in Australia, and have influenced a general shift towards health literacy being mainly positioned as a quality and safety issue on the policy agendas of state and territory governments.

In **Austria**, the ongoing healthcare reform process is mainly focused on structural aspects of healthcare, but since a lot of HL interventions need to take place in the healthcare field, it was a good opportunity to develop specific aims and interventions to improve HL in the healthcare sector, especially after the publication of the results of the HLS-EU study which showed low scores for the country. This was also the reason why one of the ten inter-sectoral health targets set by the Government was entirely devoted to the improvement of HL in the population, and set as a top-priority.



Portugal also build its plan in line with a health services reform named “SNS + Proximidade” (NHS+Proximity), that aims to place the citizen in the centre of the health system. The NHS + Proximity was created with the objective to modernize the National Health Service, bringing it closer to people. This project is supported by citizens, health professionals, academics, managers and industries. The new HL action plan is seen as an opportunity to reassess the needs and to update the Health Plan so that it is more focused and directed towards the current needs.

In **Scotland**, there was a strategic momentum to conceive a HL action plan with the 2020 Vision for Health and Social Care (<http://www.scotland.gov.uk/Topics/Health/Policy/2020-Vision>) launched in 2011. This reform of the social security system integrating Health and Social care (Welfare reform programme) aims at achieving sustainable quality in the delivery of healthcare services across Scotland, with a focus on prevention, anticipation, supported self-management and person-centred care. The Healthcare Quality Strategy for NHS Scotland launched in 2010⁷⁸ <http://www.scotland.gov.uk/Resource/Doc/311667/0098354.pdf> and the Patient Rights Act 2011 reinforced this insight; the latter aims at improving patients' experiences of using health services and to support people to become more involved in their health and health care (<https://www2.gov.scot/Topics/Health/Policy/Patients-Rights>). So did the launching, in England, of the Health Foundation's [MAGIC \(MAking Good decisions In Collaboration\)](#) improvement programme to support clinical teams in primary and secondary care to embed shared decision making with patients in their everyday practice (culture change work towards shared decision-making)⁷⁹ This also emphasised that “*shared decision-making should not be confined to a single one-to-one interaction between a patient and clinician but that it had to be embedded across the whole healthcare team, between people and their families or carers, and their wider community*”.(Kramer, 2019, p430.⁸⁰)

The second Scottish plan is the prolongation of the first one. In the meantime, Scotland's Chief Medical Officer had published three annual reports (2016⁸¹, 2017⁸² and 2018⁸³) on ‘Realistic Medicine’ that insisted on the drive to better support people's needs through shared decision-making, with a focus on improvement of health literacy. “*Realistic Medicine proposes a change in culture and systems to move practitioners towards ‘focusing*

completely and relentlessly on what matters most to the people who look to them for care, support and treatment’. It marks a move further away from parental approaches, to a rebalanced connection between people and their practitioners with shared decision-making at its heart.”(Calderwood 2016p6⁸¹) More recently (April 2018), new [Health and Social Care Standards](#) were launched to replace the former National Care Standards (2002). Instead of separate standards for different settings, they consist of a single set of standards that are significantly more rights-based, person-led and outcome-focused. One of the standards is that: “*I am supported to make informed lifestyle choices affecting my health and wellbeing, and I am helped to use relevant screening and healthcare services.*” Scotland also mentions the influence of global movements such as Choosing Wisely (www.choosingwisely.org/) that have brought a focus on supporting people to make better decisions about care.

4.2 Development of the HL Plans

4.2.1 Initiation of the HL Plans

The HL policies and action plans were initiated by the public authorities in four out of six countries in this study (AT, AUS, SCOT, POR), whereas the initiatives raised from the associative sector in the two others (NL, IE). This is a fundamental difference in the chronological sequence. When the plan is initiated by the authorities, it is implemented top-down from the governmental bodies towards the field actors (whoever they are) while when the policy arises from the associative sector, the movement eventually moves upwards from the field and all existing activities towards the governmental bodies, for coordination and subsidies.

The action plans originating from the **public authorities** do not necessarily proceed from the Ministry of Health of the country. It is indeed the case for **Portugal** (Ministério da Saúde, Direção-Geral da Saúde) and **Scotland** (the Health & Social care Dept. of the Scottish government, in collaboration with NHS Scotland). In **Australia**, the initiative originates from a specific body within the health authorities, i.e. the Australian Commission on Safety and Quality in Health Care (ACSQHC). On the contrary, in **Austria**, the plan is an initiative of the *whole* government (Austrian Council of Ministers, in collaboration with the Federal Health Commission), which has to be related



to the fact that the Austrian government chose for a Health in All Policies approach.

The two examples of initiatives arising from the associative sector show quite different dynamics. In Ireland, the whole organisation is driven by one charity (and lobbying) organisation (NALA), whereas in the Netherlands, the picture is rather that of a mosaic of actions facilitated by an umbrella association of field actors and more broadly embedded within the framework of a national programme for prevention:

- In **Ireland**, the National Adult Literacy Agency – NALA (<https://www.nala.ie>) is an independent charity funded in 1980 and entirely devoted to the improvement of literacy in adults (thus they are not limited to health literacy). NALA works in partnership with several departments of the Irish Government (Dept. of Health, Dept. of Children and Youth Affairs, Dept. of Education and Skills), with the HSE (the governmental organisation managing the health services throughout the country), the statutory agencies, with community and voluntary bodies, and with the private sector.
- In **the Netherlands**, the HL promotion is endorsed by the National Alliance for Health Literacy (Alliantie Gezondheidsvaardigheden) which is a non-governmental collaboration (on a voluntary basis) of more than 80 academic institutions, research and knowledge institutions, health care professionals and provider organisations, patient representative organisations, industry and business, health insurers and local institutions and initiatives. This organisation was established in 2010.⁸⁴ But the Alliance also aligns since many years with a governmental initiative (Alliantie Gezondheid en Geletterdheid), an inter-sectoral initiative of 5 Ministerial Cabinets (including Public Health), within the framework of a national program for prevention 'Alles is Gezondheid (2014-2017, 2017-2021) (www.allesisgezondheid.nl). The latter focuses on the improvement of literacy in general, which implies that its scope is broader than the scope of the National Alliance for Health Literacy. The rationale of the Alliantie Gezondheid en Geletterdheid is that problems in people with reading, writing or calculating can have a direct and negative effect on their health and health behaviour.⁸⁵

Coordination of the collaborative activities is done by Pharos (<https://www.pharos.nl/english/>).

The development of programmes and activities regarding health literacy can thus occur **without the existence of a national action plan or policy**. According to Van der Heide et al⁸⁴, the organisation and implementation of activities related to health literacy seem more dependent on other factors like the awareness of the concept of health literacy, the presence of a dense associative sector or NGOs, the organisation of the healthcare systems, the conceptions of citizens' rights and of course, the availability of financial incentives.

Table 3 summarises the origin of the studied action plans and policies.

Table 3 – Initiative of the studied HL action plans

Public initiation of HL Action Plan	Associative sector initiation of HL Policy
<ul style="list-style-type: none"> • AUSTRIA: the Austrian Council of Ministers and the Federal Health Commission⁷² • AUSTRALIA: the Australian Commission on Safety and Quality in Health Care (ACSQHC) • PORTUGAL: the Ministry of Health – Directorate-General of Health (Ministério da Saúde, Direção-Geral da Saúde) • SCOTLAND: the Scottish government (Health & Social care) + NHS Scotland 	<ul style="list-style-type: none"> • IRELAND: the National Adult Literacy Agency (NALA) • NETHERLANDS: the National Alliance for Health Literacy/Alliantie Gezondheidsvaardigheden now connected with the framework of a national programme for prevention



4.2.2 Political contexts of the studied policies and action plans

The political organisation of the country – its degree of federalisation – and the context of its health system are key factors in the nature and scope of action plans and policies.

In **Australia**, the federal government and the state and territory governments have a shared responsibility for the health policy and the management of the healthcare system. This multi-tiered system makes it difficult to have a coordinated action and people often end up working in silos: *“the work that is being done is not consistently known and applied across sectors, settings, professions, agencies, and health and healthcare environments and consequently opportunities for researchers, healthcare providers, healthcare organisations, consumers and policy makers to learn from each other are hampered. Current systems to support improvements in health literacy at a local, regional, and state and territory level are variable, and are absent nationally.”* (ACSQHC, 2014, p.30⁷¹) This fragmentation and lack of coordination was the rationale for developing the statement at the federal (‘national’) level, in the hope of having all health Ministers to agree upon it, which would help all health departments to acknowledge HL as a priority. As a matter of fact, the Australian “plan” is actually a “national statement”; it does not constitute a formal government policy, but the fact that it was endorsed by all federal, states and territory health ministers signals an in-principle commitment to addressing health literacy across Australia.¹¹ The central government agency ACSQHC supports national action to address health literacy in a systematic way, with a focus on promoting and providing useful resources to support healthcare organisations to address health literacy in their local environment. Some states have elaborated their own HL action plan that meets their state’s needs, as the states vary in their need, structure, and approach.

However, a program of health reform has been under way in Australia since 2010, which aims to improve the effectiveness, efficiency, appropriateness and accessibility of health care. Work is occurring in eight key streams of health reform: hospitals, general practice and primary health care, aged care, mental health, national standards and performance, workforce, prevention and e-health.⁸⁶ HL has been integrated the National safety and

quality health service (NSQHS) standards as a criteria within the Partnering with Consumers Standards.

Austria is another example of federated country. The Austrian Ministry of Health, the Austrian ‘Länder’ (Federal subdivisions) and the health insurance funds have shared responsibility for the health sector, but the influence of the national state is rather limited compared to the ‘Länder’. Consequently, there are numerous differences in service provision for the population in the different provinces.⁷⁴ As already mentioned, the Austrian HL Plan corresponds to one of the 10 health targets set by the Federal Government.⁷² These targets are based on a number of common principles (“orientation towards health determinants”, “health-in-all-policies approach” and “promoting health equity”). However the whole Health Targets process is mainly a declaration of intent with scarce implementation power (Austria lacks political mechanisms to implement a real inter-sectoral approach).⁸⁷ As for the reform of the whole healthcare system (Zielsteuerung-Gesundheit), it is independent from the governmental Health targets initiative, and mainly focused on structural aspects of healthcare.

At the other end of the scope of federal/federated countries, we studied the Scottish HL action plan. **Scotland** is a nation within a federation of countries (UK) and is autonomous for the management of its health care sector, just like England, Wales and Northern Ireland. Since there is no UK-wide policy on health literacy, the HL-action plan was set up by the Scottish Government together with the National Health Service (NHS) Scotland and it is also part of a wider approach to transform the health and social care in Scotland.

In **Portugal**, the Ministry of Health works at a national, regional and local level on the mainland. The Azores and Madeira archipelagos, as autonomous regions, have broad powers for their own health care planning and management. All policy implementations that promote health literacy are considered at all these different levels. The HL Plan takes place within the implementation of a National Health Plan, of which principles of “Citizenship in Health”, “Equity and Access to Health Care”, “Quality in Health”, “Healthy Policies”, objectives and goals guided the elaboration of the HL plan.⁸⁸



As already mentioned, the HL action plan was launched in a context of deep reforms of the whole healthcare system in several of the studied countries.

In **Ireland**, the Irish government launched a new health policy named “Healthy Ireland: A framework for improved health and wellbeing 2013-2025”.⁷³ The commitment towards HL is a (small) part of this reform.

In the **Netherlands**, HL actions seem more independent from the health system; they really arise from the societal network and do not have a strong “medical” aspect. HL is rather considered from a patients’ rights perspective (see Box 4)

4.2.3 *Methods used to develop and to run the HL action plans and policies*

4.2.3.1 *Stakeholders and experts consultation*

In **government-driven HL policies**, the public authorities often set up a **working group with a large number of stakeholders** to coordinate and implement the action plan. When the plan comes from the associative sector, the concerned organisations take on this responsibility, eventually with the support of the authorities.

The working groups can be **permanent** as it is the case in **Austria**, which has set up an Inter-sectoral Platform on Health Literacy (Österreichische Plattform Gesundheitskompetenz - OEPGK) (see Box 3). This platform was created to coordinate the achievement of the Health Target n°3, specifically dedicated to HL. The elaboration of the ten Health Targets relied on a large consultation process of all relevant political and social stakeholders (more than 40).⁷² Moreover, during this elaboration process, everyone interested in the topic was invited to express views and opinions through an online platform. The results of the online participation were incorporated in the development of the targets.

In the example of **Scotland**, the working group was **temporary and ad hoc**: for the first plan, a “National Health Literacy Action Group” (NHLAG) called on the expertise of a representative panel of people working in the field encompassing public health, policy, academia, clinical practice, rights and health equity and health and knowledge information. It was chaired by the Chief Executive of an alliance representing associative sector organisations and people with disabilities, living with long-term conditions or providing volunteer care. The NHLAG adopted a collaborative and evolutionary approach by approaching successively the definition of the problem and concepts, the development of an overarching ambition, the definition of the specific scope and the prioritisation of specific actions. The group met approximately every four weeks for two years. In addition, the Scottish Government appointed a GP as a national clinical lead for health literacy. For the second plan, a new working group was set up, the Scottish Health Literacy Action Plan Implementation Group (SHLAPIG) to replace the first one.

Portugal combined the two types of working groups. They first chose for a leapfrogging approach, convening several successive working groups composed of Portuguese experts, WHO experts, various stakeholders (not necessarily in relation with HL), within local government, education, health professions, academia, the media and civil society, in order to wrap up all the information gathered to build a first draft of the plan. Then they set up a more permanent Monitoring Commission of 15 experts from different backgrounds (public health, marketing, psychology, information systems, consumer representatives...) to support the prioritization of actions and measures, and as a resource of excellence for development of strategic information and to guarantee the follow-up.⁸⁹

In **Australia**, the whole process was conducted by an **existing official body**, the ACSQHC (Australian Commission on Safety and Quality in Health Care) which organised the consultation process. They began with establishing a stocktake to identify policies, programs and other activities that were being undertaken to address health literacy. This was done through a consultation of the state and territory health departments, other government agencies, health services, advocacy organisations, consumer organisations and a range of others. Data was collated and the activities were clustered into themes. This first step was not meant to be



comprehensive, but it gave initial insight into the types of activities occurring and what people viewed as health literacy. Then they did a literature review (published and grey literature) and carried an overview of policies implemented in different countries. On this basis, a draft document describing the impact of health literacy on safety and quality and the conceptual framework as such was submitted to national consultation. All stakeholders and the public were invited to comment and provide open ended input, face to face interviews were conducted with representatives of all state and territory health departments, people from health services, consumers etc. Finally they drafted the final version of the background paper and statement.

Box 5 – The Inter-sectoral Austrian Platform on Health Literacy (Österreichische Plattform Gesundheitskompetenz - OEPGK)

The OEPGK was created to support both the wider public health-oriented health target process and the more specific reform of the healthcare system. Its implementation has taken the Health in All Policies (HiAP) approach into account. It relies on participative and cooperative coordination in its management, with a “core team” consisting of 3 representatives of each of the 5 constituting groups: the federal government, the 9 Länder, the health insurance funds, the HiAP partners (i.e. other ministries: Education, Labour, Social welfare, Sports, Science&Research, Public Services, etc.) and representatives of its (more or less) 50 member organisations (partners of the healthcare, education and welfare systems, as well as societies and NGOs). It is chaired by the Federal Ministry of Labour, Social Affairs, Health and Consumer Protection. To keep the OEPGK operational, there is a coordination structure and team in place which is located at the Austrian Health Promotion Fund. (for more details about the history and organisation of OEPGK: see Nowak 2019 p 458⁷⁴).

The work of OEPGK is organised on concrete focal points by working groups spanning all policy areas, but with a strong focus on healthcare. Depending on the topic, the working groups always include different members of the core team as well as experts from relevant organisations. The working groups develop concrete strategy concepts and practical tools to improve health literacy. They do not address the population directly, but the tools and trainings provided by the working groups are meant to empower professionals who reach out to the population. So, the aim is to empower as many professionals as possible. Scientific concepts, methods of measurement, evaluation, impact research or the results of target group-specific interventions on the topic of health literacy form the theoretical basis for practical measures.

To become a member of OEPGK, organisations need to submit a structured description of a HL intervention, which is then evaluated by the core team. Membership is limited to the duration of the intervention. However, new ways of partnerships are envisaged, like recognition processes.

For instance, an organisation could be recognised as a partner without having a specific intervention ongoing, but because of its fulfilment of specified criteria (e.g. to be able to prove that the way it runs its core processes is beneficial for the health literacy of one or more target groups of the organisation, for example, a hospital that is routinely training its personnel in patient-oriented communication). There is already a recognition for trainers filling the quality criteria requested by the platform.⁸⁷

4.2.3.2 Evidence-based

It is very difficult to appraise to which degree the different HL policies and action plans rely on strong evidence, because it is not systematically mentioned in their official documents and brochures. Nevertheless the Scottish, the Australian and the Austrian plans present extensive bibliographies referring to a large body of international scientific papers related to the recommended interventions. However, there is very little evidence regarding the evaluation of the HL action plans and policies.



4.2.3.3 Existing actions or new ones

Another interesting aspect of the methodology for developing action plans is to what extent they are **based on existing interventions or, on the contrary, implement new actions**, and the criteria for choosing one way or the other. The two countries where the plan started from the associative sector quite naturally relied mainly on existing activities supported by already active organisations. However, an important difference between these two countries has to be mentioned: while NALA in **Ireland** seems to be the one and only actor promoting literacy over the whole country, the National Alliance for Health Literacy in the **Netherlands** was set up to gather all existing initiatives in the country (where health promotion has been a tradition for decades) under a common umbrella in order to coordinate them.

The **Portuguese** plan includes and promotes existing actions, and develops new ones. The existing actions were evaluated through a set of 12 criteria developed on the basis of the CHRODIS criteria (EU Joint Action for Chronic Diseases⁹⁰)

In **Australia**, the National Statement acknowledges the existence of “*many pockets of excellence and innovation contributing to a patchwork of health literacy activity*”. Initially, the first draft of the Statement was based on a mapping of those existing actions.

In **Austria**, all interventions submitted to the OEPKG had initially to be new in order to avoid window-dressing, but it turned out that this condition could rule out important pre-existing interventions, so some compromises had to be done and some interventions actually are reshaped pre-existing ones.⁸⁷

Box 6 – The Dutch Alliance

In the Netherlands, where there is no dedicated HL plan as such, the National Alliance for Health Literacy (*Alliantie gezondheidsvaardigheden*), a non-governmental voluntary network of more than 80 members from the associative, academic and private sectors, was set up. They work on a common agenda of sharing knowledge and experience, facilitating networking, advocating for the incorporation of health literacy into operations of health institutions and planning joint actions.^{20, 23} The National Alliance for Health Literacy focuses on the development of instruments to be used by healthcare professionals for contacts with people with low health literacy. It also organises working groups in the field of research, education and patient participation. What the individual partners do depends on their own mission and objectives, and is not determined by the Alliance.

The National Alliance works in close collaboration with a governmental initiative, the Alliance Health and Literacy (*Alliantie Gezondheid en Geletterheid*) under the form of a national prevention plan “*Alles Is Gezondheid*”. The Alliantie Gezondheid en Geletterheid counts more than 3000 partners. It focuses on literacy in the broadest sense, which implies that its scope is broader than the scope of the *Alliantie Gezondheidsvaardigheden*.⁸⁵

The Prevention Plan “*Alles Is Gezondheid*” stimulates a national movement to improve the level of language for people with low literacy skills.¹⁵



4.2.4 Financial resources

There is a clear difference in funding between government-led HL policies and associative-driven programmes. In the first case, the funding remains purely public, whereas NGOs and associative initiatives often rely on private resources, be it charity, public-private partnerships or private sponsoring.

Publicly-driven HL action plans	Associative sector-driven HL Policies
<ul style="list-style-type: none">• AUSTRIA: inter-sectoral platform OEPKG is publicly funded; interventions are partly funded by the authorities and partly by health insurance funds. No private money.• AUSTRALIA: the Australian Commission on Safety and Quality in Health Care (ACSQHC) is cost-shared by federal and state & territory health agencies.• PORTUGAL: funding by the Directorate-General of Health; no external funding.• SCOTLAND: the Scottish Plan is funded by the Scottish government (Health & Social care) + NHS Scotland.	<ul style="list-style-type: none">• IRELAND: the National Adult Literacy Agency (NALA) is a charity. The main private sponsor of their HL activity is the pharmaceutical MSD.• NETHERLANDS: the National Alliance for Health Literacy / Alliantie Gezondheidsvaardigheden works in partnership with more than 3000 partners, from governmental bodies to community centres, health care organisations and private groups.

In **Austria**, as already mentioned, the inter-sectoral Health Targets process has not much implementation power. Consequently, there are not much resources allocated to it and the member organisations of the Platform have to find resources on their own (eventually by asking for a public subsidy) to finance their interventions.⁸⁷ The selection of an intervention depends thus on offers made by participating experts and stakeholders who have the power and means to get action into practice. These stakeholders have to be convinced to invest in HL, either by new interventions or by (re-)shaping already planned interventions with an additional focus on HL.⁷⁴

With regard to the Austrian Healthcare reform, the Ministry of Health, the 9

Länder and the umbrella of the health insurance funds have adopted a joint agreement to allocate financial means on the pre-defined topics. They represent the main financing for HL interventions – with the limitation that these occur mainly within the healthcare sector. National activities are financed by the Ministry of Health and health insurance funds; regional activities are financed by the Austrian federal states and partly also by health insurance.

The resources of the Austrian inter-sectoral platform OEPKG are allocated by the [Austrian Health Promotion Fund](#) (FGÖ = national funding agency for health promotion, division of the research and planning institute for health care (GÖG) in Austria). Although the money from the Austrian Health Promotion Fund guarantees some independence for the platform, it complicates long-term planning since decisions on the Fund's resources are taken by a board of trustees who follow a rather puristic understanding of health promotion that does not extend to interventions in the healthcare field. Therefore, the Fund and the partners of the OEPKG constantly have to convince the trustees to maintain investment in the OEPKG.⁷⁴ More details about the budget of OEPKG can be found in the supplement.

No private money went into health literacy interventions in Austria so far (apart from the early measurement of health literacy in Austria that was co-funded by MSD). However this could possibly change in the future because the resources of the public sector are scarce when it comes to the work to be done. This will only happen at the conditions that all partners agree and that it occurs in a completely transparent way.

In **Australia**, there is no funding attached or provided to the National Statement, which has to be considered as a framework for services and systems to use as a basis for improving the safety and quality of care, and as a guide to help them identify which area they may want to focus on. There are also requirements for health services in the National Standards that they provide information that is easy to understand and use, and improve wayfinding and navigation. This is part of their quality improvement process and there is no funding attached – although state health departments, local health districts may decide to provide funds locally.



As for the Australian Commission on Safety and Quality in Health Care (ACSQHC), it is cost-shared by federal and state & territory health agencies. Work such as the National Statement on Health Literacy was developed in partnership with stakeholders across the system, and endorsed and agreed by all Health Ministers.

In **Scotland**, the government is working collaboratively with colleagues across the health and social care landscape – NHS Scotland, the third sector and voluntary sector – to deliver the actions set out in the 'Making it Easier' plan.

In **Portugal**, the action plan was developed and funded by the Directorate-General of Health; there was no external funding.

In **Ireland**, the multinational pharmaceutical company MSD started a collaboration with NALA in 2007 when it was decided that HL should be key element of their corporate social responsibility agenda. In April 2009, MSD sponsored a survey amongst 1,000 GPs to examine their views on patient communication. This survey showed that 69% of GPs were not aware that almost 50% of the Irish population had low literacy skills. Following that, MSD has also sponsored an audit of health literacy in healthcare settings (www.nala.ie/research/health-literacy-audit/). MSD is currently the main sponsor of the Crystal Clear MSD Health Literacy Awards, designed to identify best practices and to reward innovation in the field. Currently, NALA and MSD run the Crystal Clear accreditation programme for GPs and pharmacists based on an online audit of nine questions.

In the **Netherlands**, the national program for prevention 'Alles is Gezondheid' (www.allesisgezondheid.nl) works in partnership with more than 3000 partners, from governmental bodies to community centres, health care organisations and private groups.

4.3 Content of the HL action plans and policies

4.3.1 Beneficiaries of the action plans and policies

In all countries, the HL action plans/policies cover the entire population, groups. However, some countries choose to follow a 'life cycle' approach, paying particular attention to certain periods of life. This is particularly the case in **Portugal**, which considers children/adolescents, adults/parents and the elderly, and which also focuses on critical moments of transition (e. g. university entrance, labour market entry, retirement...).

Besides, all countries also put a focus on certain vulnerable groups whose definition varies. **Ireland** defines the vulnerable groups as follows: people with disabilities, health and mental health problems, the unemployed, disadvantaged communities and minority groups. In **Austria** the vulnerable population consists of persons over 65, low-income, migrants, educationally disadvantaged groups, persons with chronic illness..., and some sub-policies are targeted to specific groups (e. g. people with impaired hearing).

In the **Netherlands**, HL interventions are spread over all groups in society (depending on the partner-organisation activity) including vulnerable/minority groups and HL in occupational environments. The current (fifth) prevention program (PP5) focuses on development of knowledge for schools, neighbourhoods, work environments, care and health prevention.⁹¹

4.3.2 Announced goals and strategies

When it comes to more specific goals, this study will use the 3 levels classification proposed by Murugesu et al¹³ which can be summarised as follows:

- Micro-level: improving the health literacy-friendliness of the interaction between individual patients and health (and social) care professionals. This level encompasses interventions targeted at individual citizens/patients (especially in vulnerable groups) as well as interventions targeted at the individual professionals (best practices, education...);



- Meso-level: improving the health literacy-friendliness of the healthcare services at the level of the healthcare institutions or practices (organisational HL);
- Macro-level: improving the health literacy-friendliness of the society as a whole by implementing a Health in All Policies (HiAP) approach, which means a global policy statement and the mobilisation of other sectors (education, welfare, economy, ...), the involvement of key actors such as the health insurance funds, the professional associations, etc. The setting of a HL-research agenda can also be seen as a macro-level goal, be it by assessing the needs of the population (measurement of HL in the target population, development of tools adapted to a specific population), by monitoring the plan itself and assessing its results, or by participating in international HL-studies.

There is a wide variety within the goals of the studied action plans and policies. They range from a very concrete micro/meso-level (Scotland) to a very global 'Health in All Politics' macro-level (Austria's ten targets). There are almost no quantitative targets; the only one found is the Austrian target to improve the proportion of Austrians with "sufficient" and "excellent" health literacy in the overall index of the HLS-EU to 55 %.

Awareness raising is the most frequently mentioned goal across the different action plans, as it can be considered as the common denominator – or the first condition – of any policy aiming at the improvement of HL within a country. Awareness raising can be meant at a global level (macro-level: make the whole society aware of the importance of a good level of HL in order to reduce health inequities) or more specifically directed towards the health professionals (meso-level: quality of healthcare).

In **Australia**, the goals of the national statement are rather situated at the level of increasing awareness and fostering a climate of national action and collaboration on health literacy (macro-level), with a specific point of attention for the integration of HL in education, but the political commitment is limited to providing a framework. This must be put in line with the federal organisation of the Australian territory, where the individual states and territories have a large autonomy for what concerns their health policies. Some states have developed their own HL-plans (e.g. South Wales), but they are largely autonomous in that respect, which allows them to adapt the

general framework to the specific needs of their population. The National Statement commits to promote and provide resource materials (but no funding) at the local level for healthcare organisations to improve their health literacy environment.

The picture is somehow similar in **Austria**, which is also a federated country. The inter-sectoral Health Target number 3 on HL sets three priorities, one on each level: micro-level (improve individual HL with a focus on vulnerable groups); meso-level (improve the health literacy-friendliness of healthcare services); and macro-level (improve the health literacy-friendliness of the whole economic system). However, these goals remain rather vague – especially for the macro-level. Much more concrete goals are expressed within the ongoing healthcare reform, even though HL is only a marginal issue in that deep-going process. These goals are a mix of micro- and meso-levels: improve the quality of communication in healthcare (by training healthcare professionals), improve the quality of written and audio-visual information (by providing writers, financiers and publishers of information with a set of criteria and skills); improve the health-literacy responsiveness of organisations (by providing self-assessment tools and guidelines for organisational HL); empower citizens and patients (currently by an adaptation of the Ask-me-three campaign for Austria). The last goal is a macro-level goal: monitoring the health literacy of the population (currently by coordinating the European Network on Measuring Population and Organisational Health Literacy – M-POHL, and by a national participation in the network).

In **Portugal**, the national HL plan aims at *“increasing HL levels among the Portuguese population in a sustainable way, enhancing the ability of people to navigate the Portuguese National Health Service within the context of their everyday lives and improving self-care and disease management.”*⁹² In the official document of the HL plan, 4 goals are mentioned, but they seem broader than the mere HL domain. Therefore, one can assume that they must rather be seen as 'action areas' than as real goals: 1/ adopting healthy lifestyles; 2/ enabling adequate use of health system; 3/ promoting well-being (in chronic disease); 4/ promoting knowledge and research. There is an additional focus on some global national health objectives such as improving the quality of life for people over the age of 65, or reducing obesity and the percentage of smokers.



In **Scotland**, the ultimate goal of the HL plan is definitely meso: to reach a healthcare culture and practice which supports equal access, collaborative working and self-management. This means making it easy to access health services, have better conversations with the professionals, and be in the driving seat of one's health and healthcare: *"We want Scotland to be a health literate society which enables all of us to have sufficient confidence, knowledge, understanding and skills to live well, on our own terms, and with any health condition we may have."* The underlying reason is that they realised that there were already existing actions in the educational system (Scotland's National Curriculum was already addressing functional literacy and numeracy along with digital literacy, with a focus on health, wellbeing and personal development) and within communities, both in people's neighbourhoods and online, though these initiatives lacked of accessibility and links with social and health networks. But on the other hand, they were struck by the lack of responsiveness by the healthcare system to the demands, expectations and obstacles it was unwittingly placing on its users. *"As a national health and care system, we needed to get our own house in order"* (Kramer, 2019, p.424⁸⁰).

The Scots have chosen for a progressive approach, setting their first goals at micro level: awareness raising within the workforce, improving access to HL techniques and resources for the health professionals in order to improve their capacities to address low HL (existing best practices), developing new tools and innovations in new enabling approaches, specific attention to transitions of care (hospital discharge, informed consent, changes in medication). Plan 1 (Make it Easy) was thus mostly aiming at improving capacities of individual health professionals to address low HL.

The second plan builds on the first one but is more oriented towards organisational HL (meso-level) in that it aims at (further) designing supports and services to better meet people's health literacy levels.

The government-led Healthy **Ireland** plan is a general health plan not specifically devoted to HL. One of the policy themes is 'Empowering people and communities' with the aim of *"fostering the implementation of mutually reinforcing and integrated strategies and actions to encourage, support and enable people to make better choices for themselves and their families"*. Twelve actions are proposed under this theme, with only one specifically mentioning HL. But other actions can be seen as promoting HL in the broad

sense and in a cross-sectoral way, as for instance: *"Support, link with and further improve existing partnerships, strategies and initiatives that aim to increase the proportion of young people who complete full-time education"*. More concrete actions towards improving HL are to be found on the field, where the NALA charity develops many interventions and acts as a strong lobbying force by putting HL on all agendas: research, awareness raising, training and accreditation of the healthcare professionals, and integrating HL considerations into all national health campaigns and screening projects.

In the **Netherlands**, there is no HL plan as such but the aim of the National Alliance is to reduce health inequalities and focusing on people with, among others, limited health literacy. This is embedded in an inter-sectoral national program for prevention 'Alles is Gezondheid (2014-2017, 2017-2021) (www.allesisgezondheid.nl).

All goals announced in the studied action plans are summarised per country in a table in the supplement.

4.3.3 Actors

In line with the three levels of goals, the actors called upon by the HL action plans can also be divided into three levels (with unavoidable overlaps):

At the macro-level, the governmental bodies are the indispensable *primum movens* actors. At the best, they can impulse a Health in All Policies approach (as in **Austria**) and mobilise sectors other than the health sector for cross-sectoral actions: education (schools, universities), municipalities, media, social networks, academic researchers, private sector. All these sectors can also be considered separately as macro level actors in that they can instigate policy interventions on own initiative in their field of action.

The meso-level encompasses the whole health sector, which means all healthcare institutions and practices from the largest hospitals to small private practices, the health insurance funds, the professional organisations of healthcare providers, etc. **Scotland** systematically adds to the 'health workers' the word 'social', putting the focus on the social aspect as an essential component of healthcare. In **Austria**, they also mention the scientists in public health and the health promotion experts who can develop and evaluate programmes and interventions. The **Australian** plan also



insists on the role of the ‘nonclinical workforce’ such as receptionists, volunteers, kitchen staff and cleaners, who often interact with consumers and have an important role in creating an environment where it is easier for people to navigate, understand and use health information and services.

The micro-level focuses on the interaction between the citizen and the health system. Consequently, the two protagonists must be considered: the healthcare providers and the individual patients/citizens. On the one hand, all individual health (and social) care providers must be deemed accountable for contributing to a better quality of their interaction with the patient and therefore (be educated to) make use of specific techniques and tools in that aspect.

On the other hand, the individual citizens/patients, their relatives, their representative organisations or communities also have to be made aware of their own rights and responsibilities in their healthcare and health status, and all means must be made available in order to reach that aim. When it goes about citizens or patients, the actors are thus identical to the beneficiaries, but considering them as actors is a way of empowering them.

Patients and self-help organisations can influence health policy decisions. It is also strongly recommended to involve them in the development of tools and campaigns targeting the lay public in order to be sure that the results really meet the needs they were aimed at.

Austria also mentions specific actors from the civil society like teachers, persons involved in extra-curricular youth work, women’s health centres, enterprises, municipalities, etc., and in **Scotland**, they have a specific action with public libraries. A peculiarity of **Australia** is that they rather talk about ‘consumers’ than about ‘patients’.

All actors involved in the studied action plans are summarised per country in a table in the supplement.

4.3.4 Partnerships

The extraction grid of this study makes a distinction between “Actors” and “Partners” but in practice, these two items largely merge and overlap. Some countries describe an extensive list of partners whereas others just mention that the HL action plan “necessitates a large cross-sectoral collaboration”.

The **Portuguese** HL action plan broadly mentions several partners such as “Public, Social and Private Sectors, Ministries and Interministerial Commissions, universities, professional orders and scientific societies, NGOs, media (incl. social and digital media), civil society, patient associations, etc.”

In **Austria**, the focus is mainly set on “actors” (see 4.3.3) but partnership as such is mentioned in the composition of the inter-sectoral platform, which gathers representatives from the federal government, the 9 Länder, the health insurance institutions, the HiAP partners (i.e. other ministries: Education, Labour, Social Affairs, etc.) and around 50 member organisations (partners of the healthcare, education and welfare systems, as well as societies and NGOs).

In **Australia**, the national statement does not mention any partners as such either, but encourages a long list of actors to undertake actions: consumers, consumer organisations, healthcare providers, healthcare organisations, governments, educators, regulators, peak bodies, researchers, etc. The ACSQHC works in partnership with patients, carers, clinicians, the Australian state and territory health systems, the private sector, managers and healthcare organisations. Work such as the National Statement on Health Literacy was developed in partnership with stakeholders across the system, and endorsed and agreed by all Health Ministers.

In the **Netherlands**, partnership is the very essence of the HL policy. More than 80 organisations work on voluntary basis under the umbrella of the National Alliance for Health Literacy (www.gezondheidsvaardigheden.nl) – which facilitates collaboration and networking). The members of the Alliance are academic institutions, research and knowledge institutions, health care professionals and provider organisations, patient representative organisations, industry and business, health insurers and local institutions and initiatives.⁸⁴



In **Ireland**, the HL action plan is supported by a multi-stakeholder collaboration regrouping the National Adult Literacy Agency (NALA: <https://www.nala.ie/>), the Departments of Health, Children and Youth Affairs, of Education and Skills; the Health Service Executive; statutory agencies; community and voluntary bodies; university departments and the private sector (the pharmaceutical company MSD).

The **Scottish** HL action plans rely on numerous partnerships, namely with the Health and Social Care Alliance Scotland which is “the national third sector intermediary for a range of health and social care organisations” (<https://www.alliance-scotland.org.uk/>). The Alliance has over 2,700 members including large, national support providers as well as small, local volunteer-led groups and people who are disabled, living with long term conditions or providing volunteer care. Many NHS Boards, Health and Social Care Partnerships and Primary/Community Care practices are associate members and many health and social care professionals are Professional Associates. Commercial organisations may also become Corporate Associates. Other partners are the Scottish Public Health Network (<https://www.scotphn.net/>); the Scottish Council for Voluntary Organisations (SCVO: <https://scvo.org.uk/>) and the Patient Partnership in Practice (P³) network (<https://www.rcgp.org.uk/rcgp-near-you/rcgp-nations/rcgp-scotland/rcgp-scotland-patient-group.aspx>), which is a group run by the Royal College of General Practitioners of Scotland, that represents the views of patients, and provides the patient perspective and experience when the College responds to consultations or developing strategies and policies. Health insurance funds do not seem to be partners here.

Thus, to some extent, all the studied policies bring together field organisations from the non-profit sector and official /political instances. In some cases, as in Scotland, the policy deploys top-down to meet and involve the associative network and ask for their support, whereas in other patterns, the impulse grows from the field to finally receive a political support, as in Ireland and the Netherlands.

4.3.5 Actions

This study classified the different types of interventions found in the studied policies and action plans according to the macro-meso-micro levels (also with unavoidable overlaps). Given that the analysis of the interventions is not within the scope of this study and to avoid too many redundancies, this study will summarise the types of actions in this section without giving details per country. The interested reader can find details and full references of all action plans per country in the appendix of this report.

4.3.5.1 Macro-level

While the goals of the studied action plans were often referring to **macro-level trans-sectoral policies**, we did not find many concrete examples of such actions. **Australia** specifically mentions the education of children: some programs have been implemented at a national level to improve general literacy and health literacy (example of a (non-governmental charity) program to teach children about health: <https://www.lifeeducation.org.au>).

Regarding **health policy actions**, more examples can be found:

- embed HL into government legislation, policies and plans (e.g. implementing policies that prioritise HL in program planning);
- embed HL into standards and funding mechanisms (e.g. altering funding mechanisms to encourage awareness and action on HL);
- systematically include HL and health promotion as part of the professional competencies of all healthcare providers and social workers;
- systematically include communication, conversation and empowerment skills as part of the professional competencies of all (future) healthcare providers and social workers;
- develop standards for evidence-based communication training for of all healthcare providers and social workers, according to the Calgary Charter⁹³;
- consider communication, conversation and empowerment skills as a criteria for the accreditation of healthcare professionals;



- consider to integrate (self-)audits for health literacy friendliness into the standards for health care;
- fund and launch awareness raising campaigns, population health programmes, health promotion, education and social marketing campaigns, etc.;
- generalise the use of patients' electronic health-records and accompany this use with the necessary support in order to make them real tools for empowerment.
- Finally, macro-level actions also encompasses funding of and participation in national and international **research initiatives**, like the participation in the European Network on Measuring Population and Organisational Health Literacy (M-POHL) survey (**Austria** as coordinating country, **Ireland, the Netherlands, Portugal**) or in other international initiatives like the WHO European Region Action Network on Health Literacy for Implementation of Prevention and Control of NCDs (**Portugal**).

4.3.5.2 Meso-level

- Embed HL into policies, procedures and practices of healthcare organisations in order to make them HL-friendly;
- Develop practical toolkits, audits and quality standards for literacy-friendly healthcare settings (e.g. Vienna Health Literate Organisation (V-HLO) self-assessment tool, Enliven Organisational Health Literacy Self-assessment Resource, Org-HLR);
- Develop trainings for the healthcare and the communication staff within healthcare settings;
- Develop trainings for primary healthcare;
- Promote approaches that support more meaningful conversations in order to ensure that health and social care providers understand what matters to the persons receiving care;
- Promote walkthrough and wayfinding approaches in order to identify organisational barriers in care institutions such as inconsistent

signalisation, confusing appointment letters, etc.; develop a demonstration (geographical) site for a health literacy responsive organisation;

- Make use of new technologies to organise care around the patient (e.g. Modern Outpatient Programme aiming at empowering outpatients in order to reduce the inappropriate visits to hospital and to signpost patients to the right clinician at the right time and right place);
- Collaborate with citizens' panels to explore how to further strengthen relationships between healthcare professionals and individuals;
- Encourage improvements towards a 'health-literacy friendly health insurance';
- Sustain intercultural mediation services.

4.3.5.3 Micro-level:

1. Towards patients and citizens

Actions to strengthen access to quality information

- Provide reliable information related to health topics: books, websites and portals, digital platforms, telephone lines...+ develop tools and guidance to adapt this information to the needs of the targeted public (also by involving patients' representatives as experts to ensure that the developed documents and tools really meet the needs of the patients);
- Develop educational programmes in health promotion (for consumers, children, migrants, vulnerable groups...);
- Integrate HL considerations into national health campaigns and screening projects;
- Launch social marketing campaigns.



Empowerment actions

- Implement communication techniques inspired by the "Ask me 3" concept;
- Provide and accompany access to one's own electronic health-records;
- Promote self-management, shared decision making and anticipated care planning conversations;
- Offer 'HL coaching' focused on strengthening individual health competences (obtaining reliable information and being able to make good use of it);
- Train committed members of a community (e.g. migrants) to become 'champions' or 'pilots' and propagate information in their community and build a HL champions network.

2. Towards healthcare professionals:

- Develop awareness raising campaigns among healthcare workforce about the consequences of low HL among the patients;
- Provide trainings, online guides, etc. to develop interpersonal communication skills: use of plain language, decision aids, shared decision-making processes, educative and recall strategies (e.g. Teach-back, Ask-tell-ask, Teach to goal, Ask me 3, Chunk & check, use of simple language, use of pictures, help with paper work...). Key here are the health literacy universal precautions, i.e. approaching all patients with the assumption that they are at risk of not understanding their health conditions or how to deal with them, and subsequently confirming comprehension, so that the risk of miscommunication is minimized^{35, 94} (see Box 1);
- Provide recognition awards on the basis of HL characteristics of the healthcare provider's practice .

4.4 Implementation

4.4.1 Timing

This study did not find much information about the timing of the action plans. Only **Portugal** presents a detailed roadmap with staged milestones between January 2019 and December 2021.⁶⁹ In **Austria**, the 10 Inter-sectoral Health targets are to be reached in 2032, but the healthcare reform has a much tighter timing, with a first period from 2013 to 2017 and now a second period lasting until 2021. In **Scotland**, the first plan was scheduled for the period 2014-2017, it is now being followed by a second plan from 2017 to 2025.

In the **Netherlands**, since there is no standalone national policy on health literacy, there is also no timing. The National Alliance for Health Literacy has a multi-annual work plan, the current one being set for 2017-2019.⁹⁵ The question of the timing is neither of application in **Australia** since the national statement does not set any time limits. However, the process around the standards and health services is assessed every three years.

4.4.2 Opportunities

As already mentioned, some HL action plans take place within (or in parallel to) a **reform of the healthcare system** of the country. This is the case for Australia, Austria, Portugal and Scotland.

In **Austria**, a lot of stakeholders and decision makers in public health and healthcare are convinced of the importance of HL and are ready to take action, especially after the publication of the results of the HLS-EU study which showed low scores for the country. This is also the reason why one of the ten inter-sectoral health targets set by the Government was entirely devoted to the improvement of HL in the population.

In **Australia**, consumer health organisations at a national and state and territory level now advocate for those that fund, regulate and deliver health services to recognise the importance of HL and to support consumers in that regard.

The fact that HL was explicitly included in the second edition of the National safety and quality health service (NSQHS) (mandatory) standards (Australian Commission on Safety and Quality in Health Care, 2012) has



contributed to position it as a quality and safety issue on the policy agendas of state and territory governments.

This puts the focus on increasing the responsiveness of health and social service organisations to the health literacy needs of individuals and communities. However, the downside of this is that HL is almost exclusively considered in the context of clinical care and health service delivery at the expense of health promotion-oriented policies (health education and capacity-building activities).¹¹

In their contribution to the International Handbook on HL, Trezona et al also criticised the current HL policies in their country as *“largely failing to address health literacy across key life stages and in key health-promoting settings such as in schools, workplaces and other social/community environments, despite the wide acknowledgement that health literacy is content and context-specific. Further, current policies give very little attention to the health literacy needs of specific population groups, or the need to consider factors such as culture, language, gender, sexuality and disability.”* (Trezona, 2019, p 479¹¹).

Portugal also build its plan in line with a National Health Plan; the new HL action plan is seen as an opportunity to reassess the needs and to update the Health Plan so that it is more focused and directed towards the current needs.

4.4.3 Threats

When policies are government-driven, they are vulnerable to political changes that can threaten the continuation of their mission; this was explicitly mentioned for **Austria and Portugal** (both countries were awaiting elections during the period of this study). This issue is less sensitive when the actions originate in the associative field.

In **Portugal**, incapacity of broadening the spectrum of communication to the whole population was also feared.

In **Austria**, Nowak et al see the perpetuation of the financing of HL coordination and interventions as a challenge and add that it will be important for the inter-sectoral platform to be able to demonstrate its efficiency, i.e. that its activities actually contribute to improving population

HL in Austria and that these improvements will bring about economic benefits for the Austrian healthcare system.⁷⁴ The upcoming European HL Survey (HLS-EU 2019) will probably entail some economic assessment by including the social insurance number into the survey, which will allow to have anonymised hard data on the links between HL and the actual usage of healthcare services. This could allow to get a clearer idea of the potential costs and savings of the healthcare system through better HL.⁸⁷

Austria also seems to face ideological reluctances in that many actors still think that HL is just an outcome of health education and that all it takes is more efforts to educate people. Some people are not yet convinced of the necessity for the system to improve its responsiveness as well.⁸⁷ Formal regulations will be required to encourage institutions to systematically implement the principles of health-literate organisations in their daily functioning.⁷⁴ On the other hand, parts of the public health community fears that the new focus on HL might lead to a renaissance of blaming the individual for adverse health outcomes (individual accountability) rather than concentrating on further developing the health system to meet population and patient needs (political accountability).⁷⁴

In **Australia**, the pressure on the system, leading to time-pressure and capacity was mentioned as a threat to addressing health literacy. As services get busier these types of issues are the ones that might get lost in the rush. The fact that health literacy is now incorporated in the standards does mitigate this threat to some degree, as the standards are mandatory – but this is only for part of the system (not primary care) and is not a complete picture of health literacy.

4.5 Evaluation of the HL policies and plans

In contrast with the evaluation of specific HL interventions, which is gaining importance in the literature, this study found very little evidence regarding the evaluation of the HL action plans and policies. As a matter of fact, few countries evaluate their policy at a nationwide level (for example Austria) but most of them rather opt for evaluation of individual interventions. The local correspondents for this study, who were generally strongly involved in the implementation of the policies of their respective countries, were all aware of the problem, but the field is still in its infancy and the practical hurdles are numerous.



In **Austria**, the monitoring of the inter-sectoral Health Targets takes place in coordination with the monitoring processes for other strategies such as the health reform process, the health promotion strategy and the health strategy for children and young people, which makes the overall picture a bit of a mosaic.⁸⁷ Notwithstanding this self-recognised shortcoming, it is the Austrian policy that disposes of the most advanced evaluation process. For the 10 Health targets, meta-indicators were defined with experts on the achievement of each of the targets. Within each target, indicators are to be drawn up in the respective working groups. At the level of the actions, the responsible institutions in the working group must define at least one benchmark which is designed to make the level of implementation of the measure visible. Evaluation occurs at regular intervals and the results are used to plan the next steps. The OEPGK itself was also submitted to an independent evaluation after the first year of activities. This evaluation report confirmed successful capacity-building for improving HL in Austria.⁷⁴

Additional informal elements of evaluation of the Austrian policy are also mentioned by Nowak et al in their contribution to the International Handbook on HL.⁷⁴ They regret that most interventions still take place in the healthcare sector; other important sectors are still only marginally involved (e.g. the education sector) or not at all (e.g. the economic sector despite its strong impact on (un)healthy lifestyles of the population). *“The HiAP approach is reflected in the governance structure of the OEPGK, but in real life partners from outside the healthcare system participate mostly in observational roles.”* They also deplore a lack of feedback on whether the chosen interventions actually meet their needs (no involvement strategy for the beneficiaries of the interventions). Most interventions are planned and implemented by experts and public bodies with very little involvement of patients and citizens.

In **Scotland**, evaluation was built in since the very conception of the plans but it was decided to keep it very pragmatic: *“Since the main goal of the [first] Plan was to initiate health literacy action, the evaluative priority was to explore what possibilities would emerge and how, rather than focus on specific health, personal or economic outcomes.”*(Kramer, 2019, p 424⁸⁰) For the ongoing second Plan, *“the emphasis will be on improving the quality of people’s experience with the health and care system. Simple measures such as confidence scales can show improvements in awareness,*

understanding and confidence, all of which are key markers of improved health literacy responsiveness.” (Kramer, 2019, p 424⁸⁰) The Scottish Health Literacy Action Plan Implementation Group (SHLAPIG) is in partnership to consider how best to capture peoples experience and consideration on the most appropriate areas and methods for evaluation. There is an intention to use tools such as Care Opinion (online platform for sharing of opinions and personal stories) to capture experiences, innovation and feedback for improved health literacy impact. There are no evaluation publications as yet.

Some sparse evaluations of specific interventions have been found, as for instance an evaluation of the frequency of use of the central portal website www.healthliteracyplace.org (Google Analytics and Twitter analytics) or an evaluation of the capability trainings with health and social care staff (awareness raising courses, Train the Trainer, conferences) by written feedback from participants, pre and post-training questionnaires, etc.⁹⁶

In **Portugal**, a set of indicators will be defined that will allow the assessment of the need for possible adaptations for compliance and success of the plan.

In **Australia**, the National Standards will probably be used as a means of measuring action within part of the system, but these have only just commenced implementation so it is too early to expect any results. They also intend to conduct another stocktake (mapping), but probably not before 2021 or 2022, to give local policies time to get traction. A new health literacy survey will also be undertaken by the ABS, which will allow to acknowledge any indication of change.

In the **Netherlands**, no studies were identified on the effectiveness of the HL policy but rather on individual actions. Scientific institutions in the Netherlands are very active in the development and validation of assessment instruments for HL (several publications). We also found Dutch studies focused on the quality of healthcare information provided (from the HL viewpoint)⁹⁷, effectivity of the ‘Teach Back method’¹³, patient coaching in specialist consultations⁹⁸, text difficulty and illustrations⁹⁹, and mobile phone apps.¹⁰⁰



4.6 Monitoring of Health Literacy

The WHO Solid Facts – Health Literacy (2013) recommended regular internationally comparative health literacy surveys with dedicated funding to allow a monitoring of the HL status of countries. The M-POHL Network was established under the umbrella of WHO Europe's Health Information Initiative (EHII) in February 2018 and aligned with Health 2020, the European policy framework for health and well-being. M-POHL builds on the first European Health Literacy Survey (HLS-EU) (2009-2012) which found that an average of 47% of the citizens in the 8 participating countries had limited health literacy.

The M-POHL Network aims to institutionalise a regular internationally comparative European health literacy survey of high quality and support the collection of data on population-based individual health literacy and of organisational health literacy. Such a **monitoring system** is one of the axes of capacity building at the level of each country as well as on the international level.²⁰ It is expected that the M-POHL action will enhance HL in Europe by facilitating the exchange of experiences, ensuring the availability of high-quality and internationally comparative data for benchmarking on population HL, and the HL responsiveness of health-care systems and organizations.¹⁰¹ The first project of the M-POHL Network will be a reiteration of the HLS-EU survey to objectivise the evolution of HL in the European population since the first survey in 2012. The results of this HLS-19 survey will be available in 2021.

The M-POHL Network is currently coordinated by **Austria** which also participates as country in the survey. Other participating countries are: **Belgium**, Bulgaria, Czech Republic, Denmark, Germany (North Rhine-Westphalia region only), Greece, **Ireland**, Israel, Italy, Kazakhstan, Luxembourg, Moldova, **Netherlands**, Norway, **Portugal**, Poland, Russian Federation, Slovak Republic, Slovenia, Spain, Sweden, Switzerland, Turkey, and the United Kingdom.

Scotland has been invited to participate in the survey through a joint United Kingdom involvement. To date (September 2019) discussions are ongoing but it is unlikely there will be specific Scottish data in the survey. However, the Scottish Government Health literacy team and Analytical Services Team are currently considering the most effective method how to gather data that

measures the impact of health literacy in Scotland. They envisage the opportunity to include specific health literacy questions in some of their health surveys.

With regard to **Australia**, the last national survey measuring health literacy was conducted in 2006 by the ABS (Australian Bureau of Statistics). The ABS has conducted another similar survey in 2018, following up respondents from the 2017–18 Australian National Health Survey.

4.7 Impact of the HL actions plans and policies

Though it might be too early to objectivise the impacts of the action plans and policies analysed, some trends have already been noticed in **Austria**, as reported by Nowak et al. Globally, it seems that HL has become part of the mainstream public discourse in the country. It has been included in the government programme for the period 2017-22 (but they have anticipated elections in September 2019 so this might be obsolete). A great deal of the training for future healthcare professionals has incorporated HL skills started in their curricula, and the main professional organisations also pay attention to it. The OEPKG platform attracts a rapidly growing number of members who implement various field interventions.⁷⁴ Health Literacy has also made its way into some legal frameworks, for example the social insurance act defines interventions to improve HL as a voluntary field of activities for social insurance, and the Act on Nursing defines HL as a professional core competency of nurses. The Austrian "Strukturplan Gesundheit" (OESG) – which basically describes which healthcare services are needed in which amounts across the country – lists HL as one of the responsibilities of the primary care centres that are being implemented in Austria.⁸⁷ The results of the next European HL survey HLS-19 of the M-POHL Network will be available in 2021 and will hopefully show a quantitative improvement in the HL of the population.

In **Scotland**, the launch of a second Action Plan is indeed a strong sign of impact of the first one. *"Since the implementation of the first Plan, there have been several shifts in strategic policy for health and social care. The national action plan has been helpful in embedding the principles of health literacy into these policies, which, in turn, are giving energy and movement to addressing health literacy"* (Kramer, 2019, p 429⁸⁰)



Achievements mentioned in the document 'Progress against Actions' are the following:

- greater awareness across the NHS in Scotland, giving workers more skills to support better health literacy practice;
- people trained in the tools and techniques needed to further spread understanding;
- launch of The Health Literacy Place website as the online resource to support this work;
- clearer information available for people before appointments and when discharged from hospital;
- improvements to appointment letters, making them more considerate of people's communication needs;
- better information to improve safety and support for people to self-manage their healthcare, particularly for drugs such as warfarin are.¹⁰²

The already mentioned 3 annual reports (2015⁸¹, 2016⁸² and 2018⁸³) on Realistic Medicine by Scotland's Chief Medical Officer Catherine Calderwood can also be considered as an impact from Plan 1 in that they insisted on the drive to better support people's needs through shared decision-making with a focus given to improving health literacy as a key element. In return, being a support for Realistic Medicine is an openly claimed purpose of the second Plan.

5 OPTIONS FOR A BELGIAN HEALTH LITERACY POLICY PLAN

This study was requested as a preliminary step to an eventual Belgian federal policy action plan. Such a plan is needed in Belgium, certainly as health literacy is a crucial determinant for health and has a critical impact in health inequalities, and as the long-term vision note on sustainable development adopted by the federal government (2013) states that the Belgian health system must contribute to "improving the health status of citizens" and to "reducing health inequalities".

The present report is the result of an international comparison of the HL policies of six countries selected for their relevance in the field of HL action and/or because their political situation gives an interesting perspective in relation to the political context of Belgium. The resulting recommendations are intended only to create the necessary conditions for the development of an action plan (capacity building), but remain very preliminary steps. They deliberately remain general in nature because their purpose is limited to giving a vision of the paths that could be followed.

5.1 Health literacy capacity building for Belgium

The screening of policies from different countries highlights a range of very different and sometimes divergent trends, but also avenues of convergence. Bearing in mind the latest international reports that have marked the evolution of HL policies at European level (see 1.4), it can certainly be said that addressing the challenge of low literacy in the population of a given country requires the public health system to invest in the six dimensions of health literacy capacity building (see 1.5).



5.1.1 Governance

The WHO Regional Office for Europe Health evidence network synthesis report highlights that health literacy involves more than just health systems and education systems: it must take place *“in the context of everyday life: at home, in the community, at the workplace, in the health care system, the marketplace and the political arena”*, as well as, increasingly, the media, social media and digital health.(Rowlands, 2018,p viii³²) Indeed, the challenge is much larger than the sole question of healthcare. All sectors of society should be involved – education, social welfare, employment, sports, consumers, public services... This requires a synergistic set of cross-sectoral policies, ideally grown out of a “Health in all Policies” approach and objectivised through the setting of health targets. Many recommendations were found about this in the international literature, but unfortunately, concrete examples in the studied countries were very scarce.

In a federated country like Belgium, a *Health in All Policies* (HiAP) approach entails different levels of competencies, which renders the implementation complex and requires a strong cross-sectoral and multilevel collaboration. This is especially critical for sectors like education (see Box 3), employment or the media.

Different levels of competences would also have to be mobilised *within* the health sector, as a large part of the health literacy challenge implies interventions in prevention and health promotion issues (which are the responsibility of the regions). A Belgian plan can thus only function if the federated entities are involved together. This means that the setup of a cross-sectoral task force and of an inter-ministerial conference on health are the indispensable first steps.

At the level of health policy actions, some examples show that HL can be embedded into legislations, policies and plans (e.g. implementing policies that prioritise HL in program planning), or into standards of care and funding mechanisms (e.g. altering funding mechanisms to encourage awareness

and action on HL). It can also be a HL-friendly political decision (whatever the level) to fund and launch awareness raising campaigns, population health programmes, health promotion, education programmes in schools, social marketing campaigns, etc.

There is a global trend towards activation and empowerment of the patients/citizens. Approaches like self-management, shared decision making or anticipated care planning conversations are already gaining importance in our country; they must be further encouraged and this can also be done through some or other form of political stimulation. An underpinning condition for this is to provide reliable and accessible information to the lay-public. Examples were seen in several countries: creating national health information websites, low-threshold 24 hours telephone information service, guidance for journalists and organisations who publish information on health, etc.

Vulnerable populations require additional efforts. They should be identified and reached through specific means. The already existing initiatives should receive support and acknowledgment.

Giving all individuals access to their own electronic health-record is also an empowering trend in full expansion. This implies the need for people to have adequate eHealth literacy skills^b and, in the broader sense, adequate digital Literacy^c. Indeed, it is insufficient to provide access to electronic patient records if citizens do not have sufficient skills or competences to deal with these digital tools or if they cannot make distinction between reliable and poor health-related knowledge and information.

However, it must be clearly stated that empowering citizens and patients cannot constitute the only principle of a HL policy, in that this would put the whole responsibility on the sole shoulders of the individuals. Because empowering is a process, it is never complete and requires a continuous effort, not only to improve the empowerment but also to avoid its reduction.

^b The ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem. ¹⁰³

^c The ability to use information and communication technologies to find, evaluate, create, and communicate information, requiring both cognitive and technical skills. ¹⁰⁴



5.1.2 Knowledge development

The results of the European Health Literacy Survey have played a triggering role in almost all the studied countries. Belgium did not take part in it, but similar studies have shown that the level of HL within the Belgian population was similar to the European average. With the recent decision that Belgium would take part in the next survey (M-POHL network) it can be expected that a continuous monitoring of the HL level of the Belgian population will follow. This would ideally require a research infrastructure that allows for the systematic collection of relevant high-quality data and the development of indicators.

It will be important to analyse the determinants and consequences of low health literacy in the Belgian population in order to define the context and specificities of the policy-to-come. A comprehensive capacity-mapping should be launched, which means a systematic assessment of all existing capacities (skills, competencies, structures, partnerships and resources).²⁰ The literacy-friendliness of the systems and organisations and the effectiveness of the existing interventions should be assessed. This can form a solid basis for the definition of targets for the policy, as well as for robust evaluations in the future. However, many initiatives also exist outside of the field of healthcare and/or are often not labelled “health literacy”. These interesting opportunities for HL-actions have the advantage that they can be mobilised (almost) without requiring new resources. However, they must be identified.

Throughout this whole study, it has been difficult to establish to what extent the different HL policies and action plans studied rely on strong evidence, because it was not systematically mentioned in their official documents and brochures. Neither could the local experts clarify this issue. Nevertheless the Scottish, the Australian and the Austrian plans present extensive bibliographies referring to a large body of international scientific papers. However, with regard to evaluation, the harvest was very lean, and most of the evaluations we found were focused on individual interventions (which should not be an argument for not implementing evaluations of the policy-to-come).

5.1.3 Workforce development

Healthcare professionals are the main interface of the population with the health system, but, as shown by the surveys of the health insurance funds (see 3.1.3) many patients still have problems in ‘understanding what the doctor says’. In our country as in the other countries studied, the vast majority of the healthcare professionals still has to be made aware (1) of the impact of a low-level of HL on the health outcomes of their patients, and (2) of their own responsibility in the HL-friendliness of their interaction with the patient. Awareness raising within the healthcare sector should probably be the very first step in this respect in Belgium.

Healthcare professionals are trained to interact in terms of human relations and empathy, but this is not enough to improve patients' health literacy. They also need the competences and skills to adapt their ways of communicating and interacting with people, and of empowering them. This should be systematically considered as an important part of the training and the professional competencies of all healthcare providers. The key message to be delivered to the individual healthcare professional is that of the health literacy universal precautions (see 4.3.5 Actions): address all patients with the assumption that they are at risk of not understanding their health conditions or how to deal with them, and subsequently confirm comprehension.^{35, 94} This implies getting acquainted to the use of simple strategies like Teach-back, Ask-tell-ask, Teach to goal, Ask me 3, Chunk & check, etc. Belgian healthcare professionals are also increasingly sensitized to the importance of patient-oriented approaches and shared decision making processes, but the use of these techniques probably still has to be further expanded. Informal as well as formal learning strategies, dissemination of best practices, guidelines and tools are also required in this respect; the example of the Austrian nationwide network for knowledge exchange is a very interesting example.

Incorporating HL-friendliness in accreditation and certification programmes for health practitioners is another way for the authorities to push HL into day-to-day practices. Standards and certifications for evidence-based communication training should be developed, according to the Calgary Charter.⁹³



On the other hand, it is equally important to be able to rely on a large and well-trained workforce of specialists in health education and health promotion. Indeed, the individual citizens/patients, their relatives, and their representative organisations or communities also have to be made aware of their own rights, roles and responsibilities in their healthcare and health status. Important levels of action are the provision of reliable information through all (traditional and modern) communication channels and sustaining/accompanying local community-based initiatives. Public health campaigns and screening projects should also pay attention to the HL-friendliness of the conveyed messages. Of notice is that developing tools and guidelines to adapt this type of information to the needs of the targeted public should always involve patients' representatives as experts to ensure that the developed documents and tools really meet the needs.

5.1.4 Organisational and institutional capacity

Health-literate organisations '*make it easier for people to navigate, understand, and use information and services to take care of their health*' (Brach et al, 2012, Ten Attributes of Health Literate Health Care Organizations³⁶ p 2 - see also Box 2). As such, the concept of organisational health literacy acknowledges that in addition to an individual's abilities, the demands and complexities of health and social care systems are also vitally important.

In the last decade much research has been done on this theme, generating plenty of ways to act on health literacy by addressing the organisational level of the healthcare sector. Very interesting tools have been issued, like practical toolkits for literacy-friendly healthcare settings (e.g. Vienna Health Literate Organisation (V-HLO) self-assessment tool, Enliven Organisational Health Literacy Self-assessment Resource, Organisational Health Literacy Responsiveness self-assessment tool (Org-HLR)), as well as technological tools to better organise care around the patient (e.g. Modern Outpatient Programme), training modules for healthcare professionals within healthcare settings or in primary care, etc. Interventions are possible in various areas and levels of organisational functioning: strategic planning, management change, policies and procedures, quality systems, recognition and reward systems, etc.

Original empowering initiatives in collaboration with patients have emerged (e.g. wayfinding tours of patients in hospitals in order to identify barriers to sound understanding of the each other within the institution). In some countries, citizens' panels are mobilised to explore how to further strengthen relationships between healthcare professionals and citizens. Also health insurance funds are concerned in becoming more HL friendly with their members.

Such approaches can be initiated at the level of individual healthcare institutions and organisations, but they will gain in strength and scale if they are supported by the (federal or regional) health authorities. As mentioned before, they can be integrated into policies, procedures and quality standards for healthcare organisations.

5.1.5 Partnerships

Health literacy is not only a concern for the healthcare sector. It also requires the mobilisation of all sectors of the society, at local (community), national and international level, endorsed by politicians, civil society and the private sector. Several examples of partnerships for health literacy at national level have been studied in this report. One is the National Alliance for Health Literacy in the Netherlands (see Box 6) which unites more than 80 organisations to work on a common agenda of sharing knowledge and experiences, advocating for the incorporation of health literacy into the operations of health institutions and facilitating joint actions. Another one is the National Health Literacy Advisory Panel in Ireland, which groups the National Adult Literacy Agency, the Department of Health and the Health Service Executive, as well as university departments and the private sector. A third interesting example of a constructive partnership is that of the Austrian Inter-sectoral Platform OEPGK, where representatives from all the involved federal and regional ministries (Education, Labour, Social welfare, Sports, Science&Research, Public Services) and agencies sit together with representatives from the third sector and the health insurance funds.

In most of the studied countries, the elaboration of the HL action plan was endorsed by a platform or a specific working group gathering representatives for all the involved authorities, sectors and organisations. The constitution of such a platform was often preceded/followed by a large



stakeholder consultation. The working group was either limited in time (Scotland) or permanent, subsequently taking over the rollout and the coordination of the plan (Austria), or even the two, like in Portugal (successive advisory groups led to a first draft of the plan, followed by a more permanent commission to support for the implementation and the follow-up). The stakeholders involved in the elaboration of the action plan are thus often the ones endorsing its rollout and subsequent coordination.

The coordination role is of utmost importance, whatever the structure endorsing it. In Belgium, a myriad of small-sized initiatives are running at the micro-level, the majority of them emanating from the associative sector (with some pilot-projects funded by the federal or federated authorities) and the health insurance funds. They are not comprehensively enumerated as this was not the purpose of this study, but as a matter of fact, this mosaic of well-intended efforts is a sign of vitality and could be a strong basis for the development of a Belgian HL-policy. However, there is currently no coordination between these initiatives; everyone plays on its own ground, sometimes even in rivalry. Initiatives to promote these actions, give them visibility, offer them a guidance and disseminate them as good practices, like the Daniël de Coninck fund managed by the King Baudouin Foundation or the HealthNest awards, can be seen as significant first steps in the direction of a HL policy.

5.1.6 *Financial and non-financial resources*

No changes can be expected without adequate resources. Consequently, any form of HL policy involves the guarantee that appropriate resources (financial, human and administrative) are made available for the involved actors. Quantifying these resources was not within the scope of this research; moreover, almost no information on this subject could be gathered either in the literature or through the contacts with local experts.

Regarding financial means, one interesting observation is that calling on private resources does not seem to be a taboo in the countries where the health literacy activities lie in the hands of the associative field. In the Netherlands, the umbrella of the National Alliance for Health Literacy hosts industry and business next to its other members (academic, healthcare professionals, patient organisations, health insurances and community-

based initiatives). In Ireland, the pharmaceutical MSD could even be seen as the initiator (at least financially) of the interest for health literacy and still is the main sponsor of the activities of the National Adult Literacy Agency (NALA). In Austria, the first assessment of health literacy in the population was also co-funded by MSD.

On the opposite, private funding does not seem to be called upon in countries where policies are conducted by public authorities. If Belgium opts for an associative, bottom-up policy, the way of public sponsoring or even of public-private partnerships could be interesting to explore, provided that precautions are taken to avoid opportunistic or utilitarian use of this sponsoring. As a matter of fact, Belgian associative sector stakeholders already count on private resources through the MSD-funded Health Literacy Awards, now MSD HealthNest.

5.2 Three possible paths

The action plans and policies examined in the international comparison for this report are quite diverse in scope, focus and depth. All of them have qualities and shortcomings and some of them probably correspond better to the Belgian context.

5.2.1 *Conceptual?*

In Austria, the global picture is very ambitious. The Ten Health Targets are in line with the holistic recommendations of the WHO, in the way that they were conceived within a HiAP approach involving numerous sectors (education, social welfare, employment, sports, public services, etc.). However, these targets are rather a declaration of intent, without much implementation power. Such a far-reaching policy requires huge joint efforts from several sectors, and a long-standing process of defining health targets. Moreover, its efficacy is still unknown since there is no available global evaluation yet (and few financial resources).

The same picture applies to Australia, where the 'National statement' does not constitute a formal government policy, but rather a commitment to addressing health literacy across the states and territories. This commitment is mainly aiming at creating the facilitating conditions for the federated states to implement their own local action plans.



These two examples show that plans or statements taken at the federal level are broadly inter-sectoral, but with a rather weak lever for action. It may not be a coincidence that both these plans come from countries with a high degree of federalisation. In both countries, the national action goes parallel to an ongoing reform of the healthcare system where the concrete HL actions take place (but then with a much narrower focus). But even if such inter-sectoral goals can be seen as declarations of intent, they are to be kept in mind because they can be a symbol of the country's determination to introduce the concern for health literacy throughout its whole political system, and at all levels of competences.

In Belgium, there are signs from the political level showing interest for the development of a federal policy: the federal coalition agreement of October 2014 as well as the policy note of the Minister of Health, the parliamentary motion of the deputies Ine Somers, Damien Thiéry and Jan Vercammen in 2016 and of course, the fact that the KCE was mandated to produce this report. That interest could be concretised by embedding HL into legislation and/or regulation regarding the healthcare policy.

5.2.2 Pragmatic?

In Scotland, the first action plan was almost exclusively targeted towards the healthcare sector, truly encouraging all professionals to question themselves and to adapt to patients' level of HL. From this rather 'modest' start, Scotland now progressively broadens the scope towards other fields of the society in the second action plan. One might summarise this approach as "we have to start somewhere, so let's begin with what is within reach". However, it has to be mentioned that Scotland's National school curricula were already addressing literacy issues with a focus on health and healthcare, and that there was already a vast amount of activity, support and advocacy within communities.

By focusing on the healthcare workforce – at large – Scotland seems to have succeeded in mobilising a very constructive energy on the most critical interface between the population and the health sector, i.e. where people are directly confronted with their own health issues. The message was very skilfully crafted to generate enthusiasm and mobilise goodwill. The fact that the plan addresses a tiny (5.5 Mio inhabitants), very united nation has certainly played a role as well.

However, limitation to the healthcare sector is a pragmatic choice that unavoidably would rise critics about its lack of cross-sectorality.

In Belgium, levers are certainly to be found within the actual context of ongoing reforms, like it was the case in Australia, Austria and Portugal. At organisational level, the current reform of the global hospital landscape can be a good opportunity to introduce HL into the functioning of the newly reorganised institutions. At the level of primary care, there are also new opportunities, like the Vlaams Instituut voor de Eerstelijns (VIVEL) in Flanders and the Plateforme de première ligne wallonne (PPLW) in Wallonia.

5.2.3 Or no plan at all?

A third option is: no plan at all. This is more or less what we can observe in countries like the Netherlands and Ireland, where the authorities have delegated the initiatives about HL to a very active and dynamic civil society. As a matter of fact, the HEALIT4EU project states that *"a policy does not seem to be a requirement for the development of programmes and activities on health literacy: overall, policies and initiatives on health literacy were identified in 16 EU countries. Many different stakeholders are active in the development of activities on health literacy. Often both government and NGOs together initiate and conduct activities. In addition, national 'Networks' or National Working Groups on health literacy have an important advocacy role and act as a platform for exchange between research and practice."* (Heijmans 2015 p 8¹⁵) In Belgium, we also have dynamic civil actors and even if our associative network is not as dense as in the Anglo-Saxon world, we also have 'pockets of excellence' on the field. So delegating the impulse of a HL policy to the associative sector – provided that this goes together with sufficient financial support – would probably also be a reasonable option for Belgium.

As previously said, the current associative initiatives obviously lack sufficient coordination, visibility and amplitude. There is a need for an overarching structure that would take up the leadership and bring the best out of each project. Such a structure could grow bottom-up from the third sector field, like the Irish NALA, but it could also be steered top-down, by embedding all existing initiatives into a common prevention programme launched by the authorities (like the 'Alles is gezondheid' programme in the Netherlands).



Another interesting example of a good compromise between government-led and associative-led approach is that of the Austrian Inter-sectoral Platform OEPKG, where representatives from all the involved federal and regional ministries (Education, Labour, Social welfare, Sports, Science&Research, Public Services) and agencies sit together with representatives from the third sector and the health insurance funds. Together, they select the projects of their members which they will develop, but unfortunately, they do not have the financial means to support them.

In Belgium, since all matters related to prevention and health promotion have been federalised, regional structures like the Vlaams Instituut voor een Gezond Leven (ex-VIGEZ) in Flanders and the Agence pour une Vie de Qualité (AViQ) in Wallonia already endorse some interventions, but there is nothing at the federal “public” level. However, two remarkable ongoing initiatives cover the whole country and could eventually foster the building up of a more comprehensive policy: the projects of the Dr Daniël De Coninck Fund (managed by the King Baudouin Foundation) for primary care, and the pharma-led HealthNest. Both encompass support and guidance for small projects at community level, selected according to more or less similar criteria.

An interesting approach that could lead by example in this context is the setup of a Network Administrative Organisation to coordinate the HL activities in Belgium. This model was recently used successfully to coordinate all Belgian evidence-based practice initiatives.¹⁰⁵ The added value of this network approach is that it combines a top-down steering by the funding government(s) with a bottom-up guidance by the active players and the end users (and their representatives) in the field.

6 CONCLUSIONS

The following recommendations are based on the common characteristics of the different examples analysed in the international comparison (section 4); they also correspond to the international recommendations of recent years (section 1.4) and they are structured according to the model of capacity building presented in section 1.5. However, as there are very few evaluations to date, it is impossible to guarantee that they are evidence-based; they should rather be considered as best practices.

Given the repartition of the competencies between the different policy levels and the multiplicity of possible actions to improve the HL, it is difficult to determine exactly the respective responsibilities of each actor and certainly their exclusive responsibility. For that reason, we do not address our recommendations to specific stakeholders. For each recommendation, a collaboration will be needed if we want to reach an ideal situation.

For the same reason, it is not possible to calculate the budget impact of the recommendations but it can be done for specific measures in function of the taken decisions.

In the section 5.2, three possible paths are proposed for the development of a Belgian “action plan” – with the third one being no plan but a delegation to the associative sector. The first set of recommendations is related to the two government-led paths; they represent the prerequisites for the development of such a plan. The second set of recommendations bundles different types of interventions identified throughout this research as interesting and applicable within the Belgian context, regardless of the chosen path (even if they will be much easier to implement with the support of the authorities).



6.1 First, set the stage for a national action plan

- Promote a Health in all Policies approach by setting up an inter-sectoral task force on health literacy (education, employment, social affairs ...).
- Set up an inter-ministerial workgroup on Health Literacy in order to organize an inter-ministerial conference to coordinate actions at the different levels of the health system.
- If health targets are set for Belgium, there must at least be one dedicated to health literacy.
- Set up a platform or a working group gathering experts in HL and representatives for all sectors involved in HL in order to elaborate the plan / to coordinate all existing actions on the field. The role of this platform will vary according to the chosen model of action plan, from representative of the field in a stakeholder consultation to a leading coordinating role.
- Organise a large stakeholder consultation.
- Make an analysis of the determinants and consequences of low health literacy in the Belgian population.
- Initiate a capacity mapping by
 - systematically assessing the existing capacities (skills, competencies, structures, partnerships and resources) without limiting the search to initiatives that are explicitly labelled "Health literacy";
 - assessing the literacy-friendliness of the systems and organisations;
 - assessing the effectiveness of the existing interventions.
- Set qualitative and quantitative targets for the Health Literacy action Plan.
- Always work 'evidence-based' whenever possible.

- Invest in a research infrastructure that allows for the systematic collection of relevant high-quality data and the development of indicators.
- Provide sufficient resources to the action plan.
- Consider involving the private sector (pharma, IT, media...) to gain visibility and resources but with precautions to avoid opportunistic use of this sponsorship.
- Join international initiatives of continuous monitoring of the HL level of the population.

6.2 Then consider the following interventions

6.2.1 Governance

- Embed HL into government legislation, policies and plans (e.g. implementing policies that prioritise HL in program planning).
- Embed HL into quality standards and funding mechanisms (e.g. integrating health literacy (self-)audits into the standards for health care; adapting funding mechanisms to encourage awareness and action on HL).
- Fund and launch awareness raising campaigns, population health programmes, health promotion, education and social marketing campaigns, etc.
- Promote empowerment of the patients through approaches like self-management, shared decision making, anticipated care planning conversation, etc. Specific sensitisation campaigns, provision of facilitating tools and coaching of patients about how to communicate with their healthcare professionals should also be considered.
- Fund and launch reliable information portal designed for the lay public, as well as guidance on objective health information for the media.



- Invest in community-based initiatives as well as in initiatives targeting vulnerable populations. More generally, adapt the content and the form of the communication to the different populations taking into account cultural, educational and socioeconomic levels.
- Promote the use of electronic health-record by all citizens and invest in eHealth Literacy and Digital Literacy.

6.2.2 Workforce development

- Consider awareness raising actions and promote the health literacy universal precautions among the healthcare workforce.
- Incorporate competences and skills to communicate, interact and empower patients in the education of all future healthcare professionals.
- Incorporate competences and skills to communicate, interact and empower patients in accreditation and certification programmes for all healthcare professionals.
- Encourage the development and dissemination of training modules on HL and communication skills and techniques for all healthcare professionals; setup a nationwide network for knowledge exchange on this topic.
- Set standards and certifications for evidence-based HL and communication training according to the Calgary charter.
- Reinforce the available workforce in health education and health promotion.
- Develop tools and guidelines to adapt public health information, campaigns and projects to the needs of the targeted public. Patients and citizens should always be involved as experts to ensure that the developed documents and tools really meet the needs.

6.2.3 Partnerships

- Generate an interest for HL in the civil society and the associative sector, but make it clear that only providing clear and understandable information is not sufficient.

6.2.4 Organisational and institutional capacities

- Integrate HL-friendliness into policies, procedures and quality standards for all healthcare institutions and organisations.
- Encourage the use of practical toolkits for self-assessment of the level of organisational HL within healthcare settings (and in primary care).
- Encourage collaboration with patients' organisations and citizens' panels to explore ways to strengthen relationships between healthcare institutions and users.



■ REFERENCES

1. Rudd R. Teaching Patients with Low Literacy Skills [Web page]. Boston: Harvard T.H. Chan School of Public Health; 2019 [cited September 12]. Available from: <https://www.hsph.harvard.edu/healthliteracy/resources/teaching-patients-with-low-literacy-skills/>
2. Arner A. History of Health Literacy – Part 1 [Web page]. Omaha: Methodist College; 2009 [cited September 12]. Available from: <https://aa47.wordpress.com/2009/11/18/history-of-health-literacy-part-1/>
3. Rudd R. Health Literacy: insights and issues. In: Logan R, Sigel E, editors. Health Literacy. Amsterdam: IOS Press; 2017. Available from: <http://ebooks.iospress.nl/volumearticle/47673>
4. OECD. About PIAAC [Web page]. Paris: OECD; 2019. Available from: <https://www.oecd.org/skills/piaac/>
5. IES/NCES. Adult Literacy and Lifeskills (ALL) Survey [Web page]. Washington: National Center for Education Statistics; 2019 [cited September 12]. Available from: <https://nces.ed.gov/surveys/all/>
6. Rudd R, McCray A, Nutbeam D. Health literacy and definition of terms. In: Begoray D, Gillis D, Rowlands G, editors. Health Literacy in context. . New York: Nova Science Publishers Inc.; 2012.
7. McCormack LA, McBride CM, Paasche-Orlow MK. Shifting Away from a Deficit Model of Health Literacy. Journal of Health Communication. 2016;21(sup2):4-5.
8. Ancker JS, Grossman LV, Benda NC. Health Literacy 2030: Is It Time to Redefine the Term? Journal of General Internal Medicine. 2019.
9. Rademakers J. Kennissynthese Gezondheidsvaardigheden. Utrecht: NIVEL; 2014.
10. Heijmans M, Zwikker H, Van der Heide I, Rademakers J. Zorg op maat: Hoe kunnen we de zorg beter laten aansluiten bij mensen met lage gezondheidsvaardigheden. Utrecht: NIVEL; 2016. Available



- from:
https://www.nivel.nl/sites/default/files/bestanden/Kennisvraag_Zorg_op_maat.pdf
11. Trezona A, Fitzsimon E, S. D. Health literacy policy in Australia: Past, present and future directions. In: Orkan O, editor. International handbook of health literacy. Bristol: Policy Press; 2019.
 12. Sørensen K, Van den Broucke S, Fullam J, Doyle G, Pelikan J, Slonska Z, et al. Health literacy and public health: a systematic review and integration of definitions and models. BMC public health. 2012;12:80-.
 13. Murugesu L, Heijmans M, Fransen M, Rademakers J. Beter omgaan met beperkte gezondheidsvaardigheden in de curatieve zorg; kennis, methoden en tools. . Utrecht: Nivel; 2018. Available from:
https://nivel.nl/sites/default/files/bestanden/Beter_omgaan_met_beperkte_gezondheidsvaardigheden_in_de_curatieve_zorg.pdf
 14. Joseph-Williams N, Elwyn G, Edwards A. Knowledge is not power for patients: A systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. Patient Education and Counseling. 2014;94(3):291-309.
 15. Heijmans M, Uiters E, Rose T, Hofstede J, Devillé W, Van der Heide I, et al. Study in sound evidence for a better understanding of health literacy in the European Union. . Brussels: Directorate General for Health and Food Safety. European Commission; 2015. Available from:
https://ec.europa.eu/health/sites/health/files/health_policies/docs/2015_health_literacy_en.pdf
 16. Brach C. The Journey to Become a Health Literate Organization: A Snapshot of Health System Improvement. Studies in Health Technology and Informatics. 2017;240:203-37.
 17. Sorensen K, Pelikan JM, Rothlin F, Ganahl K, Slonska Z, Doyle G, et al. Health literacy in Europe: comparative results of the European health literacy survey (HLS-EU). Eur J Public Health. 2015;25(6):1053-8.
 18. Parikh NS, Parker RM, Nurss JR, Baker DW, Williams MV. Shame and health literacy: the unspoken connection. Patient Education and Counseling. 1996;27(1):33-9.
 19. Roberts J. Improving health literacy to reduce health inequalities. UCL Institute of Health Equity; 2015.
 20. Van den Broucke S. Capacity building for health literacy. In: Okan O, Bauer U, Pinheiro P, Sorensen K, D. L, editors. International Handbook of Health Literacy: Research, Practice and Policy across the Life-span. Bristol: Policy Press; 2019. p. 622.
 21. Vandebosch J, Van den Broucke S, Vancorenland S, Avalosse H, Verniest R, Callens M. Health literacy and the use of healthcare services in Belgium. Journal of Epidemiology and Community Health. 2016;70(10):1032.
 22. Dewalt DA, Berkman ND, Sheridan S, Lohr KN, Pignone MP. Literacy and health outcomes: a systematic review of the literature. Journal of general internal medicine. 2004;19(12):1228-39.
 23. Kickbusch I, Pelikan J, Apfel F, Tsouros A. Health Literacy: the solid facts. Copenhagen: WHO; 2013. Available from:
http://www.euro.who.int/_data/assets/pdf_file/0008/190655/e96854.pdf
 24. WHO. Shanghai Declaration on promoting health in the 2030 Agenda for Sustainable Development. In: WHO, editor.; 2016.
 25. WHO Regional Office for Europe. Health 2020: a European policy framework and strategy for the 21st century. . Copenhagen: WHO; 2013. Available from:
http://www.euro.who.int/_data/assets/pdf_file/0011/199532/Health2020-Long.pdf?ua=1
 26. Stormacq C, Van den Broucke S, Wosinski J. Does health literacy mediate the relationship between socioeconomic status and health



- disparities? Integrative review. *Health Promotion International*. 2018(day062).
27. Marmot M, Allen J, Goldblatt P, Boyce T, McNeish D, Grady M, et al. Fair society, Healthy lives. London: 2010. Strategic review of health inequalities in England post-2010 Available from: <https://www.local.gov.uk/marmot-review-report-fair-society-healthy-lives>
28. Levin-Zamir D, Bertschi I. Media health literacy, eHealth literacy and health behaviour across the lifespan: Current progress and future challenges. In: Okan O BU PP, Sorensen K, Levin D. , editor. *International Handbook of Health Literacy: Research, Practice and Policy across the Life-span*. Bristol: Policy Press; 2019.
29. IROHLA Consortium. Health literacy in the older population. How it can contribute to sustainable health systems. Brief for policy makers in the EU member states. . Groningen: 2015.
30. IROHLA Consortium. Making health ageing a reality: a comprehensive approach. . Groningen: 2015.
31. IROHLA Consortium. Final Report Summary - IROHLA (Intervention Research On Health Literacy among Ageing population) [Web page]. CORDIS EU Search;2015 [cited 2019/10/21]. Available from: <https://cordis.europa.eu/project/rcn/106300/reporting/en>
32. Rowlands G, Russell S, O'Donnell A, Kaner E, Trezona A, Rademakers J. What is the evidence on existing policies and linked activities and their effectiveness for improving health literacy at national, regional and organizational levels in the WHO European Region? . Copenhagen: WHO Regional Office for Europe; 2018. Health Evidence Network (HEN) synthesis report 57 (978 92 890 5319 8)
33. Aluttis CA, Chiotan C, Michelsen M, Costongs C, Brand H. Review of Public Health Capacity in the EU. public health capacity consortium, editor. Luxembourg; 2013.
34. Aluttis C, Van den Broucke S, Chiotan C, Costongs C, Michelsen K, Brand H. Public health and health promotion capacity at national and regional level: a review of conceptual frameworks. *Journal of public health research*. 2014;3(1):199-.
35. Brega AG, Barnard J, Mabachi NM, Weiss BD, DeWalt DA, Brach C, et al. AHRQ Health Literacy Universal Precautions Toolkit, Second Edition. . Publication A, editor. Rockville, MD.: Agency for Healthcare Research and Quality; 2015.
36. Brach C, Keller D, Hernandez L, Baur C, Parker Z, Dreyer B, et al. Ten Attributes of Health Literate Health Care Organizations - Discussion Paper,. Washington, DC.: National Academy of Medicine; 2012.
37. Thomacos N, Zazryn T. Enliven Organisational Health Literacy Self-assessment Resource. Melbourne: Enliven & School of Primary Health Care, Monash University.; 2013.
38. Dietscher C, Lorenc J, Pelikan J. Das Selbstbewertungs-Instrument zum Wiener Konzept Gesundheitskompetenter Krankenbehandlungsorganisationen (WKGKKO-I). Ludwig Boltzmann Institut Health Promotion Research (LBIHPR); 2015.
39. Pelikan JM, Dietscher C. Warum sollten und wie können Krankenhäuser ihre organisationale Gesundheitskompetenz verbessern? *Bundesgesundheitsblatt - Gesundheitsforschung - Gesundheitsschutz*. 2015;58(9):989-95.
40. Trezona A, Dodson S, Osborne RH. Development of the organisational health literacy responsiveness (Org-HLR) framework in collaboration with health and social services professionals. *BMC Health Serv Res*. 2017;17(1):513.
41. Trezona A, Dodson S, Osborne RH. Development of the Organisational Health Literacy Responsiveness (Org-HLR) self-assessment tool and process. *BMC Health Services Research*. 2018;18(1):694.
42. Henrard G, Vanmeerbeek M, Buret L, Rademakers J. Dealing with health literacy at the organisational level, French translation and adaptation of the Vienna health literate organisation self-



- assessment tool. BMC Health Services Research. 2019;19(1):146-.
43. Schaeffer D, Hurrelmann, K., Bauer, U. and Kolpatzik, K. (eds.). National Action Plan health Literacy. Promoting Health Literacy in Germany. Doris Schaeffer KH, Ullrich Bauer and Kai Kolpatzik, editor. Berlin; 2018.
44. Paakkari O, Paakkari L. Health literacy and the school curriculum: The example of Finland. In: Orkan Okan UB, Diane Levin-Zamir, Paulo Pinheiro and Kristine Sørensen, editor. International Handbook of Health Literacy. Research, practice and policy across the lifespan. Bristol Policy Press; 2019.
45. Buse N, Mays K, Wall G. Making Health Policy. 2nd ed.: Open University Press; 2012.
46. Cheung K, Mirzaei M, Leeder S. Health policy analysis: a tool to evaluate in policy documents the alignment between policy statements and intended outcomes. Australian Health Review. 2010;34:405-13.
47. Vancorenland S., Avalosse H., Verniest R., Callens M, Van den Broucke St., Renwart A., et al. Bilan des connaissances des Belges en matière de santé. MC-Informations 258, décembre 2014, 2014:47-54.
48. Rouquette A, Nadot T, Labitrie P, Van den Broucke S, Mancini J, Rigal L, et al. Validity and measurement invariance across sex, age, and education level of the French short versions of the European Health Literacy Survey Questionnaire. PloS one. 2018;13(12):e0208091-e.
49. Charafeddine R, Demarest S, Berete F. Enquête de santé 2018 : Littérature en santé. Brussels Sciensano 2019. HIS2018D/2019/14.440.72. Available from: www.enquetesante.be
50. Onafhankelijke Ziekenfondsen. Gezondheidsinfo: een doolhof? [Web page]. 2016 [cited 20191022]. Available from: <https://www.slideshare.net/mutlibonafziekenf/debat-health-literacy-onafhankelijke-ziekenfondsen>
51. Mutualités Libres. Etude sur la qualité de la communication entre médecins généralistes et patients. Brussels: Mutualités Libres; 2016.
52. Solidaris Institute. L'information santé en Belgique francophone. Etats des lieux, attentes de la population et impact d'internet. 2017. Available from: <http://www.institut-solidaris.be/wp-content/uploads/2017/11/InformationSanteBelgiqueFrancophone.pdf>
53. Flemish Government. Health in All Policies [Web page]. Brussels: Flemish Government; 2017 [cited 05/11/2019]. Available from: <https://www.vlaanderen.be/vlaamse-regering/visie-2050/samen-leven-2050/health-all-policies>
54. Flemish Government. Health in All Policies, Infographic. In: Flemish Government, editor. Brussels; 2017.
55. RIZIV-INAMI, Médecins du Monde. White book on access to care in Belgium 2014 Available from: <https://www.riziv.fgov.be/SiteCollectionDocuments/white-paper.pdf>
56. DeBlock M. Note de politique générale /Algemene Beleidsnota. 2015
57. SAR-WGG. Advies: Vlaams Charter van de rechten van de cliënt/patient. 2017 Available from: <https://www.vlaanderen.be/publicaties/vlaams-charter-van-de-rechten-van-de-client/patient-advies-sar-wgg>
58. Somers I, Thiéry D, J. V. Voorstel van Resolutie tot invoering van een actieplan om de gezondheidswijsheid van Belgen aanzienlijk te verbeteren 2018 Available from: <https://www.lachambre.be/doc/flwb/pdf/54/3050/54k3050001.pdf>
59. Décret relatif à la promotion de la santé 2016. Available from: http://www.ejustice.just.fgov.be/cgi_loi/change_lg.pl?language=fr&a=F&table_name=loi&cn=2016021818
60. COCOF. Plan stratégique de Promotion de la santé 2018/2022 du Gouvernement francophone bruxellois. 2017 Available from:



- <https://www.spfb.brussels/sites/default/files/documents/pro/Plan%20strat%C3%A9gique%20de%20promotion%20de%20la%20sant%C3%A9%202018-2022.pdf>
61. Calis M, Buytaert B. Oog voor Gezondheidsvaardigheden. vzw V, editor.; 2016.
62. KBS. Website Fonds Daniël De Coninck [Web page].Brussel: KBS;2019 [cited 05/11/2019]. Available from: <https://www.fondsdanieldeconinck.be/>
63. VPP. Website Vlaams Patiënten Platform [Web page].Heverlee: VPP;2019 [cited 05/11/2019]. Available from: <http://www.vlaamspatientenplatform.be/>
64. LUSS. Website Ligue des Usagers des Services de Santé [Web page].Namur: LUSS;2019 [cited 05/11/2019]. Available from: <https://www.luss.be/>
65. PRT. Website Patienten Ratt & Treff [Web page].Eupen: PRT;2019 [cited 05/11/2019]. Available from: <https://www.patientenrat.be/>
66. Test-Achats T-A. Website Test Gezond / Test Santé [Web page].Sint Gillis: Test-Aankoop / Test-Achats;2019 [cited 05/11/2019]. Available from: <https://www.test-aankoop.be/gezond/> / <https://www.test-achats.be/sante>
67. The Scottish Government; NHS Scotland. Making it Easy - A Health Literacy Action Plan for Scotland. 2014.
68. The Scottish Government, NHS Scotland. Making it easier - A Health Literacy 2017.
69. Telo de Arriaga M, dos Santos B, Silva A, Mata F, Chaves N, G. F. Plano de Ação para a literacia em saúde-Portugal 2019-2021. 2018 Available from: <https://www.dgs.pt/documentos-e-publicacoes/plano-de-acao-para-a-literacia-em-saude-2019-2021-pdf.aspx>
70. ACSQHC. National Statement on Health Literacy. Taking action to improve safety and quality. 2014 Available from: <https://www.safetyandquality.gov.au/sites/default/files/migrated/Health-Literacy-National-Statement.pdf>
71. ACSQHC. Australian Commission on Safety and Quality in Health Care. Health literacy: Taking action to improve safety and quality. Background paper. Sydney; 2014.
72. Federal Ministry of Health and Women's Affairs. Health Targets Austria - Relevance – Options – Contexts: Abbreviated version. 2012 (revised 2017) Available from: https://gesundheitsziele-oesterreich.at/website2017/wp-content/uploads/2018/08/gz_kurzfassung_en_20170626.pdf
73. Irish Department of Health. Healthy Ireland. A framework for improved Health and Well-being 2013-2025. Dublin: Department of Health 2013.
74. Nowak P, Dietscher C, Sator M. Health literacy policies: National example from Austria – A unique story and some lessons learned from an ongoing journey. In: Okan O BU, Pinheiro P, Sorensen K, Levin D. , editor. International Handbook of Health Literacy: Research, Practice and Policy across the Life-span. . Bristol: Policy Press; 2019.
75. Nutbeam D, Wise M, Bauman A, Harris E, Leeder S. Goals and targets for Australia's health in the year 2000 and beyond : report prepared for the Commonwealth Department of Health, Housing & Community Services. Sydney: Public Health Dept., University of Sydney, 1993. ; 1993.
76. Espanha R, Ávila P. Health Literacy Survey Portugal: A Contribution for the Knowledge on Health and Communications. Procedia Computer Science. 2016;100:1033-41.
77. St Clair R. Scottish survey of adult literacies 2009: Report of findings. 2010. (978-0-7559-9480-9) Available from: https://www2.gov.scot/Publications/SSAL2009Report_Of_Findings
78. The Scottish Government, NHS Scotland. The Healthcare Quality Strategy for NHSScotland. 2010. (978-0-7559-9323-9) Available from: <https://www2.gov.scot/resource/doc/311667/0098354.pdf>



79. Joseph-Williams N, Lloyd A, Edwards A, Stobbart L, Tomson D, Macphail S, et al. Implementing shared decision making in the NHS: lessons from the MAGIC programme. *BMJ*. 2017;357:j1744.
80. Kramer G, Robertson B, Easton P, Pearson A. Developing health literacy policy in Scotland: A case study. In: Okan O BU PP, Sorensen K, Levin D. , editor. *International Handbook of Health Literacy: Research, Practice and Policy across the Life-span*. Bristol: Policy Press 2019.
81. Calderwood C. Realistic Medicine - Chief Medical Officer's Annual Report 2014-15. Government N-tS, editor.; 2016.
82. Calderwood C. Realising Realistic Medicine - Chief Medical Officer's Annual Report 2015-16. Government N-TS, editor.; 2017.
83. Calderwood C. Practising Realistic Medicine - Chief Medical Officer's Annual Report 2016-17. Government N-TS, editor.; 2018.
84. Van der Heide I, Heijmans M, Rademakers J. Health literacy policies: European perspectives. In: Okan O, Bauer U, Pinheiro P, Levin D, editors. *International Handbook of Health Literacy: research, Practice and Policy across the lifespan*. Bristol: Policy Press; 2019.
85. Alliantie Gezondheid en Geletterdheid. Alles Is Gezondheid [Web page].2015 [cited 2019-10-12]. Available from: <https://www.allesisgezondheid.nl/netwerk-en-partners/alliances/alliantie-gezondheid-en-geletterdheid/>
86. Department of Health Ageing. National Health Reform: Progress and Delivery. Department of Health and Ageing (Australia); 2011.
87. Dietscher C. Validation discussion on HL policy in Austria. . In: KCE, editor.; 2019.
88. Grupo de Trabalho do Plano Nacional de Saúde. Plano Nacional de Saúde 2012-2016-Versão Resumo. 2013 Available from: http://pns.dgs.pt/files/2013/05/PNS2012_2016_versaoresumo_mai_o20133.pdf
89. Telo de Arriaga M. Discussion on HL policy in Portugal. In: KCE, editor.; 2019.
90. Joint Action CHRODIS Plus. Recommendations to improve early detection, preventive interventions, and the quality of care for people with diabetes. Definition and agreement on a common minimum set of indicators. 2017. Available from: <http://chrodis.eu/wp-content/uploads/2017/02/wp7-deliverable-recommendations-final-draft.pdf>
91. ZonMw. Evaluatie en monitoring Alles is gezondheid [Web page].Den Hague: ZonMw;2019. Available from: <https://www.zonmw.nl/nl/onderzoek-resultaten/preventie/alles-is-gezondheid/>
92. WHO-Regional Office for Europe. Portuguese Health Literacy Action Plan helps people to help themselves. [Web page].2019. Available from: <http://www.euro.who.int/en/countries/portugal/news/news/2019/01/portuguese-health-literacy-action-plan-helps-people-to-help-themselves>
93. Coleman C, Kurtz-Rossi S, McKinney J, Pleasant A, Rootman I, Shohet L. The Calgary Charter on Health Literacy In: Quebec TCfLo, editor.: Government of Canada's Office of Literacy and Essential Skills; 2011.
94. Koh HK, Brach C, Harris LM, Parchman ML. A proposed 'health literate care model' would constitute a systems approach to improving patients' engagement in care. *Health affairs (Project Hope)*. 2013;32(2):357-67.
95. Alliantie Gezondheidsvaardigheden. Werkplan Alliantie Gezondheidsvaardigheden 2017 - 2019. Utrecht: 2017. Available from: <https://www.gezondheidsvaardigheden.nl/assets/pdfs/d217333edf/Werkplan-2017-2019-Alliantie-Gezondheidsvaardigheden.pdf>



96. Murphy L. Reporting on actions from Making it Easy: A national health literacy action plan for Scotland. 2016. Available from: www.healthliteracyplace.org.uk
97. Fransen M, Dekker E, Timmermans D, Uiters E, Essink-Bot M. Accessibility of standardized information of a national colorectal cancer screening program for low health literate screening invitees: A mixed method study. Patient Education and Counseling. 2017;100(2):10.
98. Alders I, Henselmans I, Smits C, Visscher T, Heijmans M, Rademakers J, et al. Patient coaching in specialist consultations. Which patients are interested in a coach and what communication barriers do they perceive? Patient Education and Counseling. 2019;102(8):8.
99. Meppelink C, Smit E, Buurman B, Van Weert J. Should We Be Afraid of Simple Messages? The Effects of Text Difficulty and Illustrations in People With Low or High Health Literacy. Health Communication. 2015;30(12):9.
100. Elbert S, Dijkstra A, Oenema A. A Mobile Phone App Intervention Targeting Fruit and Vegetable Consumption: The Efficacy of Textual and Auditory Tailored Health Information Tested in a Randomized Controlled Trial. Journal of Medical Internet Research. 2016;18(6):e147.
101. Dietscher C, Pelikan J, Bobek J, Nowak P, World Health Organization Regional Office for Europe. The Action Network on Measuring Population and Organizational Health Literacy (M-POHL): a network under the umbrella of the WHO European Health Information Initiative (EHII). Public Health Panorama. 2019;05(01):65-71.
102. The Scottish Government, NHS Scotland. Making it Easy - Progress against Actions. 2017. (978-1-78851-011-0) Available from: <https://www.gov.scot/publications/making-easy-progress-against-actions/>
103. Norman CD, eHealth Literacy: Essential Skills for Consumer Health in a Networked World. J Med Internet Res 2006;8(2):e9. 2006.
104. American Library Association. Digital Literacy. 2019.
105. Adriaenssens J, Jonckheer P, Vriesacker K, Sonnaert M, Van Bruystegem E, Eyssen M. The Belgian EBP Network: operationalisation of processes and governance structures for the Federal EBP Programme. Health Services Research (HSR). Brussels: Belgian Health Care Knowledge Centre (KCE); 2019. KCE reports 317 Available from: https://www.kce.fgov.be/sites/default/files/atoms/files/KCE_317_EBP_Network_Report1_1.pdf