



Adult education on digital, health and data literacy for citizen empowerment

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1. Introduction

Despite the steady rise in literacy rates over the past 50 years, there are still 773 million illiterate adults around the world, most of whom are women. These numbers produced by the UNESCO Institute for Statistics (UIS) are a stark reminder of the work ahead to meet the Sustainable Development Goals (SDGs), especially Target 4.6 to ensure that all youth and most adults achieve general literacy and numeracy by 2030. While middle- and low-income countries are struggling with these general literacy aspects, the European countries have a large percentage of their adult population classified above the target levels of literacy proficiency (e.g. International Assessment of Adult Competencies Level 1). However, in Europe, more than 90% of EU professional roles require at least a basic level of digital knowledge and skills, just as they require basic literacy and numeracy skills [1]. Yet, around 42% of Europeans lack basic digital skills, including 37% of those in the workforce [2]. Thus, digital literacy has become an important aspect in the continuous education of the EU work force, and not only.

The COVID-19 pandemic has accelerated the growth and usage of the digital technologies in the health domain, on one side bringing significant advances in health and wellbeing promotion through self-monitoring and faster/easier provision of digital health services, but on the other side exacerbating health inequalities and negatively impacting on the health literacy, in particular in the case of digitally illiterate adults. Health literacy [3] is a complex construct, covering three broad elements: (1) knowledge of health, healthcare and health systems; (2) processing and using information in various formats in relation to health and healthcare; and (3) ability to maintain health through self-management and working in partnership with health providers.

Digital and Health come in hand with Data, as the current digital transformation of the healthcare systems in Europe (and worldwide) is aiming at delivering person-centric data driven prevention and healthcare through new models, where medical experts are collaborating with health informaticians, data analysts, health data scientists and clinical information officers. Digital, Health and Data are becoming even more important in prevention and social and community care. Citizen-centred self-management of health, care and healthy behaviour provides an adequate answer to the expanding health care sector, thus supporting the sustainability of it. Citizens' enhanced digital and data skills enables them to take advantage of the further development of artificial intelligence for prevention and environmental measures.

Thus, citizens must be able to understand data concepts, data handling (e.g. collection, monitoring, transfer, storage), and security and privacy aspects related to their personal and health data.

Health, digital and data literacy represent a basic combination of elements needed by the European citizens in order to better track, manage and improve their health and well-being through the use of digital tools. Because of the rapid digitalization of the healthcare system in Europe, citizens need to be proficient with their eHealth literacy skills and be sufficiently knowledgeable on the collection and sharing of digital data, as well as data privacy regulations. Digital and data literacy of citizens is also important to assess what is happening with their data and which data protection measures they can take.

TRIO aims to empower citizens through the development of a modular approach of the trio of literacies (digital, health and data), creating and designing a manual, a toolkit and a Green Paper along with a platform that will ensure customization of content to different needs. The Manual, the first deliverable of the modular approach, will start by making a definition of the average levels of digital, health and data literacy of the three age groups in the partner countries; define the criteria and necessary skills for each group and level and understand the existing gaps. This will allow to direct the learners in a bottom-up approach to look at the world with different eyes towards being in charge of their own health and well-being. Awareness will be given to contexts beyond the well-researched theoretical practices or general population approaches, to explore instead the personal perspectives of citizens, including them in the outputs, as well as the ones of policy makers.

Definitions:

- Digital literacy: refers to the skills required to achieve digital competence, the confident and critical use of information and communication technology (ICT) for work, leisure, learning and communication [4].
- Health literacy: empowers people to make positive choices. It implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions [5].
- Data literacy: is the ability to read, write and communicate data in context, with an understanding of the data sources and constructs, analytical methods and techniques applied. [6].

1.1 Aim of the national Report

The national report will be the basis for the TRIO Manual that will be released in March 2023. Target groups of the TRIO Manual are:

- Citizens of different ages and levels of education (18-35, 36-50 and 51+) by providing an integrated approach of the competences and skills on health, digital and data, empowering them to navigate in the eHealth world;
- Formal and informal educators by providing them with organised content to share with the citizens;
- Policy makers who will benefit from them to support improved person-centred health pathways.

The manual will act as a stand-alone output, but its contents will also be integrated in the TRIO educational platform with 3 main purposes:

- As preparatory material it will sensitise the learners to digital health and data sharing practices and impacts.
- As a publication disseminated at EU, national and local level, it will be a tool for eHealth-related stakeholders, and general public.
- With its underlying data collection, it will serve to refine the educational features.

1.2 Methodology

In order to achieve the above-mentioned aims, the following methods will be applied:

- Desk research in each country concerning status (including quantitative data), main challenges and existing approaches to digital, health and data sharing literacy, best-practice examples as well as training settings and contents
- Interviews in each partner country with stakeholders, experts and representatives of the target group for the training. For the interview questions see the annex.

Various scientific studies as well as national and European statistics in the field of digital, data and health literacy were used to edit and compile this national report.

This was done in an attempt to reflect the situation in the EU and the partner countries involved in the project as up to date as possible. In addition, six citizens within the above-mentioned age groups were interviewed about their digital, data and (digital) health and data literacy. During the interviews, the needs and preferences of the different age groups regarding the creation of a learning platform were assessed.

In addition to interviews with citizens, three experts from the research and health sectors were interviewed regarding their experiences and the conception of a learning platform. The experts were represented by Prof. Dr Nadine Konopik and Prof. Dr Michael Doh from the University of Freiburg. Both are active in research in the field of health and digital health literacy and also teach within this subject area. The third expert was Dr Alexander May, a practising doctor. He is in daily contact with patients in his work and on the other hand knows existing problems within the current digitalisation debate in the health sector.

2. Overview of the national health system in Germany

Health care in Germany is generally based on four different basic principles. Firstly, all citizens are obliged to be insured in Germany within a public health insurance fund. This obligation exists for instance for all those who do not exceed a gross income limit of 64,350€ per year in 2022. For those who earn more, for civil servants, for self-employed and freelancers as well as for students and for people with an income below the minimum level there is also the possibility to insure themselves "privately" [7]. The financing of the German health care system as a second principle is based on the regular payment of insurance contributions. These are financed in part by the insured and in part by the employers. The third so-called solidarity principle applies, which means that all those with statutory insurance bear the same "risk" with regard to the incurrence of health costs and thus also have the same right to medical care and continued payment of wages in the event of illness. In addition, the fourth basic concept of German health care is the so-called principle of self-administration. This means that although the state decides on the framework conditions for medical care, the further financing, development and organisation of medical services must be self-administered.

The highest body in this context is the Joint Federal Committee. It is composed of various representatives of the medical profession, psychotherapists, statutory health insurance funds, hospitals and patients. They decide, for example, which services are offered and financed in which form by the statutory health insurance providers [8]. The German health system is very complex in its functioning due to the system of federal states and the principle of self-administration. There are many different payers and actors that interact in the German health system. These include, for example, the health insurance funds as payers, the Association of Statutory Health Insurance Physicians and Dentists, the hospital association, the chambers of the various physicians and psychotherapists, the public health services or the pharmacy associations [8].

As mentioned above, the costs for statutory health insurance are shared by employees and employers and also depend on the income of the insured. The general contribution rate for statutory health insurance is currently 14.6%, half of which is paid by employees and half by employers. However, each federal state can levy its own additional contribution, which is why the contribution can vary between 14.95% and 17.1% [9].

Since the beginning of 2021, Germany has had the so-called electronic patient file (ePA), which can be seen as the first major advance towards a digitalised healthcare system. Since then, patients have the right to have such a file created electronically by their respective health insurer, although keeping such a file is not obligatory. The ePA is created by the health insurance companies at the request of the patients, but they must also fill it with data themselves. This includes examination findings, diagnoses or doctor's letters. Data that is not available digitally must be converted into digital form by the patients themselves by scanning or photographing it. Also the patients themselves determine which data they want to disclose to which actor and which data will be deleted [10].

If a treating physician wants to receive information about a patient, he or she does not have automatic access to the respective ePA. Access must always be authorised by the patients themselves. This is done by assigning a PIN, which can be used by the treating person to activate the ePA. For example, the patient's health insurance company may not simply access the data and the patient can also set only partial access to data. This is to prevent the misuse of these health data [10].

That or how the patients are informed about data protection and the function of the system mentioned is at the same time the biggest point of criticism from one of the experts we interviewed. Despite the fact that the system has been in existence for almost two years, it is still largely unknown to the general public. Only a small part of the population is generally aware of the existence of the service, which is why very few are already familiar with information on how to handle or protect data within the ePA.

An overview of one's respective insurance contracts and or its costs does not exist, at least not as an offer from the state. For this service, there are various mobile phone apps provided by the insurance companies that give digital insights into one's own contract details, tariffs and payments.

In Germany there are also various portals and apps like Clarke for instance that compare tariffs with each other and provide an overview of one's own current insurance contracts and costs [11]. This service offer is therefore organised by the private sector in Germany.

3. Overview of digital, health, and data literacy in Germany

3.1 Statistics on digital, health and data literacy

3.1.1 Digital Literacy

The digital skills of the German population are quite different with regard to some demographic and socio-economic factors. According to Eurostat figures from 2021, around 58% of the 16-29 age group in Germany have at least basic digital skills [12]. With increasing age, the basic digital skills in Germany steadily decrease; for example, only about 28% of 65-74 year-olds have at least basic digital skills.

If one looks at these data in comparison with the other partner countries of the project, it becomes clear that especially older people in the Netherlands have significantly better digital skills (see Table 1). Initiative D21 was also able to work out that the competences to identify suitable digital offers for one's own everyday life also decrease with increasing age. In Germany, for example, 69% of 14-19 year-olds stated that they were aware of suitable digital offers, while this ability decreases steadily across the age groups 30-39 (60%), 50-59 (52%), 60-69 (35%) and 70+ (26%) [13].

Table 1: Individuals' level of digital skills from 2021, by age group

	All Individuals	16 - 29	25 - 54	55 - 64	65 - 74
European Union	54	71	62	42	25
Germany	49	58	56	42	28
Spain	64	84	73	51	27
Netherlands	79	87	84	74	61
Portugal	55	85	66	36	17
Romania	28	46	34	14	4

Source: Eurostat 2021 ISOK_SK_DSKL_I21

There are also discernible differences in terms of the educational level of people with regard to their digital skills. Across all people between 25 and 64 in Germany, a share of 23% of people with low formal education have at least basic digital skills.

This proportion increases significantly for people with intermediate formal education (47%) as well as for people with a high level of formal education (73%) [12]. If we look at the older groups of people between 55 and 74 years of age in comparison, the difference between the different levels of education becomes even clearer. Thus, 60% of people in this age group with a high level of education have at least basic digital skills, while this proportion drops sharply among people with a medium level of education (32%) and a low level of education (12%). With regard to the gender factor, current figures show that digital literacy is similarly distributed in all partner countries. In the age group 16-74, for example, there are maximum differences of six percentage points between men and women in all cooperation countries [12].

Regarding the German situation, it is also interesting to note that there are strong differences in knowledge acquisition between the various educational groups. For example, around 62% of people with a high level of education are confident that they can acquire knowledge themselves on the internet. This proportion decreases sharply regarding the middle (36%) and low education groups (24%) [13].

What is also particularly striking is what a major role the country of birth plays in Germany with regard to the presence of digital competences. In the other partner countries, the differences between natives, EU citizens and non-EU citizens vary between 4 and 9 percentage points. In Germany, however, the place of birth makes a significantly greater difference. For example, the difference between non-EU citizens and natives amounts to more than 20% (see Table 2) [12].

Table 2: Individuals' level of digital skills, by location of birth

	EU Member State	non-EU state	native born
European Union	53	46	55
Germany	38	31	52
Spain	63	63	64
Netherlands	79	72	81
Portugal	59	56	55
Romania	:	:	28

Source: Eurostat 2021 ISOC_SK_DSKL_I21

Place of residence is also a factor influencing the prevalence of digital literacy in Europe. For example, around 53% of people in German cities have basic digital skills, while this proportion decreases somewhat for people in suburbs and smaller towns (47%) and with regard to people in rural areas (45%) [12].

3.1.2 Health Literacy

According to a recent study from 2021 by the University of Bielefeld, the average health literacy of the German population has deteriorated within the last seven years. It was found that about 58.8% of the German population have only low health literacy [14]. At the same time, the study showed that health literacy in Germany is unequally distributed with regard to socio-demographic variables. People with a low level of education (78.3%), people with a low social status (71.9%), people aged 65 and over (65.1%) and those with a migration background (63.1%) in particular have low health literacy levels [14].

It is also interesting that so-called navigational digital literacy (called data literacy in this report), i.e. the ability to obtain and understand information, is very low in Germany. Schaeffer et al. found that about 83% of the respondents had low navigational health literacy [14]. Differences in the competencies with regard to various subcategories were also found. The subcategories of health promotion, prevention and disease management/health care were examined. The proportion of respondents with low competences was smallest in the area of health care (45.2%). At the same time, a significantly larger proportion of the population had low health literacy in the areas of prevention (54.8%) and health promotion (67.7%) [14]. In addition, the personal assessment of health information was a particular challenge for the respondents.

Thus, about 74.9% of the participants had low level of health literacy within this area [14]. With regard to communication with medical professionals, however, the respondents had significantly better competencies. The proportion of those with low competences in this area was only 35.7%. It is clear that patients understand health information much better when talking to doctors than when they have to evaluate and classify it themselves, e.g. on the basis of information from the internet. Within these so-called "communicative health competencies", the respondents considered the understanding of technical terms (46.5%) as well as the usually limited discussion time (47.5%) as problematic [14].

3.1.3 Data Literacy

The term data literacy is defined in this report as: "the ability to read, write and communicate data in context, with an understanding of the data sources and constructs, analytical methods and techniques applied". Based on currently available statistics, the proportion of people who have basic or above basic Information and Data Literacy is considered. The European Union counts among these basic competences skills such as basic competences regarding the search for and evaluation of information and data, communication competences, competences for the creation of own content, security competences as well as problem-solving competences [12]. The Initiative D21 maps the mentioned fields of competence with specific skills. For example, the data competences examined include research skills on the internet, comparing several sources and evaluating dubious information in the digital space [13]. In Germany, there are also clear differences with regard to information and data skills when demographic and socio-economic variables are taken into account. For example, 83% of 16 to 24-year-olds in Germany stated that they had at least basic data skills. This proportion decreases steadily over the higher age groups (see Table 3). The greatest differences across the rising age groups of the partner countries in the project are found in Portugal [12].

Table 3: Individuals' level of information and data skills, by age group

	16 - 24	25 - 64	55-74	65-74
Germany	83	80	68	60
Spain	94	91	74	63
Netherlands	94	94	90	88
Portugal	97	83	53	41
Romania	74	71	45	32

Source: Eurostat 2021 ISOC_SK_DKSL_I21

As with digital skills, the level of education also plays an important role. For example, 89% of people with a high level of education stated that they had basic or above basic data skills, while this proportion decreased significantly in the groups of people with medium (77%) as well as low formal education (61%) [15].

Similar to digital literacy, there are no serious differences regarding gender in terms of data literacy. Across all participating partner countries, this difference only amounts to 2-3% [12]. The only notable difference, at least in Germany, was with regard to data analytics skills, i.e. the ability to analyse and gain insights from data or data sets. Here, 26% of the male respondents stated that they had these skills, while the proportion of women was only 19% [15].

It is interesting to note that the differences with regard to place of birth are also present here, but they are significantly smaller than in the comparison of digital skills. Thus, 79% of the natives have basic or above basic data skills, while in the groups of EU foreigners 70% and in the non-EU foreigners 67% of the respondents had at minimum basic data skills. A similar ratio is also found in the participating partner countries [12]. The differences in data skills with regard to place of residence are also not as pronounced as those in digital skills. Thus, 80% of those living in urban areas and 75% each of those surveyed in suburban and rural areas stated that they had basic or above data skills. The greatest differences based on place of residence are found in Romania (city 76% / rural 56%) [12].

3.2 Statistics on societal and economic impacts

3.2.1 Health

According to WHO data, the average life expectancy in 2019 was about 81.5 years. With regard to the last comparable value at EU level from 2017 (78.3), Germany is thus slightly above the European average [16]. However, differences can be observed when taking into account various demographic and socio-economic factors. For example, a data report by the Federal Statistical Office found that the average life expectancy for men and women also increases with rising income. For example, men with 100-150% of the median income have a 5-year higher life expectancy than men with less than 60% of the median income (see Table 4) [17].

Table 4: Average expected healthy life years, by sex and by income level

Einkommen	Männer	Frauen
< 60 % des mittleren Einkommens	71,0	78,4
60 bis < 80 % des mittleren Einkommens	73,3	79,7
80 bis < 100 % des mittleren Einkommens	75,2	80,7
100 bis < 150 % des mittleren Einkommens	76,0	82,1
≥ 150 % des mittleren Einkommens	79,6	82,8
Insgesamt	75,0	80,8

Source: Böhm 2021

The respective level of education of a person is also a factor influencing individual health. The data report, which refers to survey data from the last German socio-economic panel, shows that people with a low level of education are more likely to suffer from mental or physical ailments. With regard to physical limitations, the risk for men with low education compared to the group with a high level of education is higher by a factor of 2.3, for women by about 2.2 [17].

With regard to mental suffering, the factor was about two times higher for men and women with a low level of education compared to the group of people with a high level of education [17]. That this also has an effect on the health behaviour of the groups of people is shown, for example, by the smoking behaviour of the two groups of people. People with a low level of education have a 1.9 (men) and 2.5 (women) times higher risk of smoking [17].

Of course, age also plays an important role in individual health. For example, cardiovascular diseases increase continuously with age. The same applies to so-called widespread diseases such as diabetes [18]. However, during its last large survey of German adults, the Robert Koch Institute was able to determine that the proportion of adults who are active in sports has increased significantly since the last survey before the turn of the millennium. For example, about 45% of men and about 41% of women between 70 and 79 years of age said they were active in sports [18].

3.2.2 Participation in society

According to European data, about 73.2% of men and 73.4% of women in Germany participated in cultural activities in the last 12 months before the surveys. It is striking that gender in Germany has only a minor effect on participation in such activities. Only with regard to specific activities, such as participation in live performances, lies the proportion of women participating in Germany about four percentage points higher [19].

However, the educational level is a decisive factor in all participating partner countries as well as in the entire European Union. In Germany, for example, 86.4% of people with a high level of education participate in sporting or cultural activities. In the group of people with a medium level of education, this makes up 70.3% and in the group of people with a low level of education 60% of the people. In the European Union as a whole, this ratio is even more pronounced, with a range of about 42% between the highest and the lowest educational group [19].

Another important factor influencing participation in socio-cultural activities is income. The proportion of people participating in all the countries shown rises continuously with increasing income. What is remarkable here is that the range between the lowest income groups and the highest is slightly more or slightly less than 40% in all partner countries as well as in the EU as a whole. Only in the Netherlands is the difference only about 25%, while here also the largest share of the lowest income group, 70.5%, participates in social or cultural activities. In Germany, slightly more than half of the respondents in this income group do so (see Table 5).

Table 5: Participation in cultural activities, by income quintile

	Cultural activities (cinema, live performances or cultural sites)					
	Total	First quintile	Second quintile	Third quintile	Fourth quintile	Fifth quintile
European Union	60,0	40,1	48,3	59,2	69,1	80,3
Germany	73,2	52,5	64,7	76,9	83,8	91,0
Spain	58,5	40,7	43,7	56,6	68,0	82,0
Netherlands	83,5	70,5	74,2	85,7	91,2	95,2
Portugal	62,7	45,4	50,3	60,4	72,8	83,4
Romania	27,5	13,9	17,6	22,2	30,7	50,3

Source: Eurostat 2019: ILC_SCP0

3.2.3 Employment

In Germany, about 85.4% of 25–54-year-olds were in employment in 2019, while this share drops to about 72.7% from the 55-64 age group onwards. Beyond retirement age up to 69, about 17.9% were still working in Germany and in the age group 70-74, about 8.2% of the respondents still reported to be in employment [20]. The ratio between workers in the age groups 25-54 and those between 55 and 65 is very similar regarding the figures of the participating partner countries. Thus, the differences in employment of the above-mentioned age groups in all partner countries as well as in the EU are approximately between 15 and 20%. The increasing age of workers therefore has an influence on the state of employment. This is particularly evident for older workers aged 55 and over.

Table 6: Employment level, by age group

	From 20 to 64 years	From 25 to 54 years	From 55 to 64 years
European Union	72,8	81,5	
Germany	80,4	86,5	61,9
Spain	63,4	74,5	71,4
Netherlands	82,2	86,1	58,5
Portugal	74,1	85,6	74,7
Romania	68,3	79,9	66,6

Source: Eurostat 2022: LFSI_EDUC_A

In addition to age, however, it is above all the level of education that has a decisive influence on the individual employment status. Thus, according to figures from Eurostat, 87.8% of people with a high level of education were employed in Germany in 2021. With regard to people with a medium level of education (80.4%) and a low level of education (61.9%), the share of employed people drops slightly.

It is interesting to note here that in comparison with the other partner countries as well as the figures for the EU, the differences in the level of employment between the various educational groups are greatest in Germany (just under 26%) and Romania (just under 46%). In the partner countries Spain, Portugal and the Netherlands, the differences between the highest and lowest education groups are only between 16 and 22% (see Table 7) [21].

Table 7: Employment level, by levels of education

	(levels 0-2)	(levels 3 and 4)	(levels 5-8)
European Union	54,9	72,8	85,0
Germany	61,9	80,4	87,8
Spain	57,2	63,4	79,7
Netherlands	66,7	82,2	88,4
Portugal	69,3	74,1	85,9
Romania	42,5	68,3	88,4

Source: Eurostat 2022: LFSI_EDUC_A

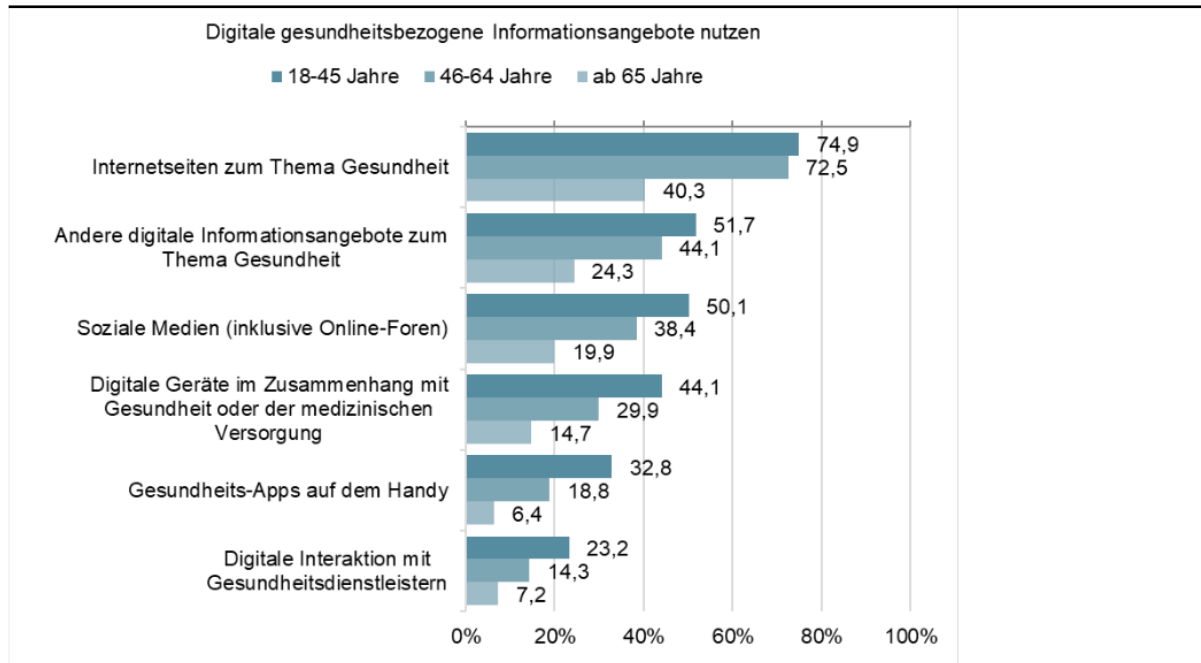
3.3 Intersectional analysis

3.3.1 Digital Health Literacy

There are significant differences in digital health literacy across the EU and the participating partner countries. This is especially the case when looking at the use of different online services. In Germany, for example, 70% of the population already used the internet to search for health information in 2020 [22]. However, if we now look at other possibilities of digital health care, it becomes clear that Germany is lagging behind both in terms of digital health skills and in terms of the infrastructures that have been created. For example, only 6% of the population in 2020 use health services via a website or app in addition to the familiar functions of making appointments or searching for information.

This is illustrated by the fact that despite the ongoing COVID 19 pandemic, only 18% of the German population used online appointments with doctors in 2020 [22]. The University of Bielefeld also found in its study of 2021 that health apps are not used at all by 79% of the population in Germany [14]. The use of digital information services decreases significantly with increasing age across all digital options (see Table 9) [14].

Table 9: Use of digital health information offers, by age group



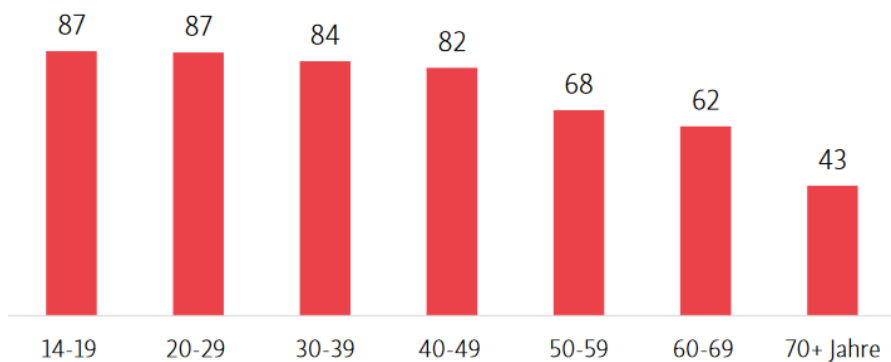
Source: Schaeffer et al. 2021: 66

Nevertheless, according to the results of the study by the University of Bielefeld, digital health literacy improved slightly during the COVID 19 pandemic, at least for younger age groups in Germany. Overall, however, the proportion of people with low digital health literacy remains high at 75.8%. Here, too, socio-demographics play an important role. In Germany, for example, people aged 65 and over (86%) and people with a low level of education (86.7%) in particular have low digital health literacy [14].

3.3.2 Digital Data Literacy

The Initiative D21 conducted a special study on the digital skills of the German population as part of the German Digital Index. According to the study, 87% of the German population are now able to conduct internet research in the area of digital data skills. 74% of the respondents already use various sources to verify information. However, this proportion decreases with increasing age in Germany (see Table 8).

Table 8: Share of people using different sources by internet research, by age groups

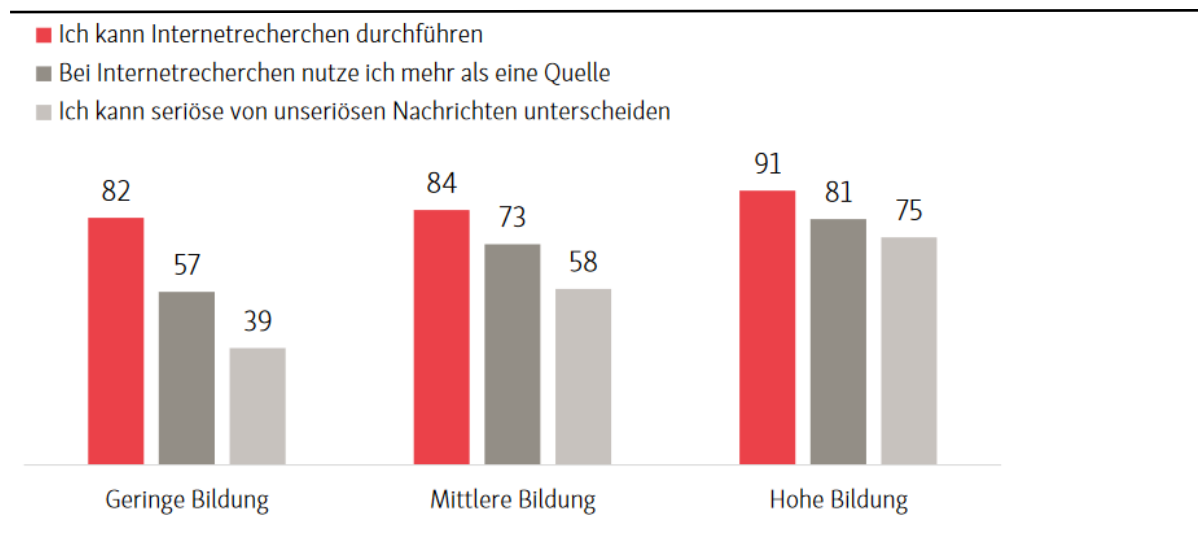


Source: Initiative D21 2021: 23

Based on the data presented, gender is only a slight influencing factor. Within the study, men stated more frequently that they inform themselves with the help of several sources than women. However, it is clear that the level of education plays a much greater role among women. The difference between the low and the high education group in the use of various sources of information is about 35%, while in the group of men it is only about 14% [13]. This relationship is also found overall across the data competencies examined.

The differences in the three competencies "researching on the internet" (red), "using more than one source" (dark grey) and "distinguishing serious from dubious news" (light grey) are most pronounced in the low education group (see Table 9) [13].

Table 9: Different Information-/Data Literacy skills, by education level



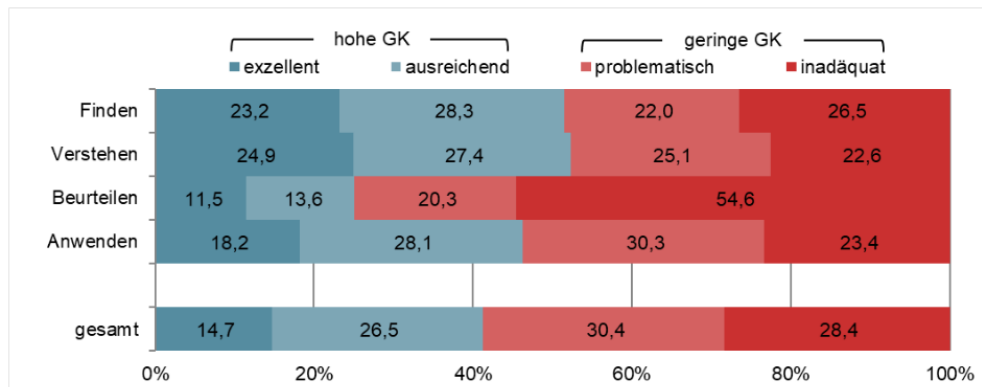
Source: Initiative D21 2021: 27

3.3.3 Health Data Literacy

Within the already mentioned study of the University of Bielefeld, it was found that the interest in wanting to know everything about one's health is more widespread among women than men, as well as for people from higher social classes and higher income groups than in the respective lower groups. No significant results could be found with regard to age [14]. At the same time, it becomes clear within the mentioned study that especially the assessment of health information is a challenge for the German population. The study was divided into the categories "finding", "understanding", "assessing" and "applying". It became clear that more than half of the population had a high level of health literacy in the area of finding (51.5%) and understanding (52.3%) health information, while about 75% of the respondents had low health literacy in the area of assessment and about 54% in the area of use and application (see Table 10) [14].

Table 10: Health literacy by different steps of information processing

Abbildung 5: Gesundheitskompetenz nach Schritten der Informationsverarbeitung (HLS-GER 2)



Source: Schaeffer et al. 2021: 26

In addition, it was found that more than one third of the respondents (34.9%) had not understood health information correctly at least once in the last year. With the addition of socio-demographic variables, it becomes clear that this primarily affected the groups of people with a low level of education (51.9%), people with a low social status (46%), people with chronic diseases (45.5%) and older people over 65 (44.9%) [14].

In this context, comprehension problems occur especially when talking to doctors. Thus, 67% of the respondents stated that they had not understood information from a specialist at least once in the last year. Such comprehension problems also occur in communication with general practitioners (33%) and health insurance companies (28.6%), but much less frequently than in conversations with specialists [14].

In this context, it is particularly interesting that the proportion of people with comprehension problems has increased by almost ten percent, especially in the 65+ age group. A current representative survey by the company EPatient Analytics, which was also supported by the Charité in Berlin, was able to obtain current data on the health data use of the population in March 2022. About 78% of respondents measure their health in some form, and about 42% already do so with the help of a digital tracking system. The most common measures are weight (75%), blood pressure (38%) and exercise and step counts (35%) [23].

4. Reported and identified gaps, needs and demands

4.1 Identified gaps

The interviewees stated that the German health care system is basically accessible to all people with regard to basic care. For example, emergencies or basic medical care were included. At the same time, however, it was noted that there was a certain inequality of treatment due to the division into those with statutory and those with private insurance. In addition, one interviewee noted that it is much more difficult for people with little language skills, for example, to understand medical contexts and information. For example, one interviewee stated, "not every citizen knows that they have the right to freedom of choice of doctor and that they can theoretically see any doctor".

Based on the studies mentioned and the assessments of citizens and experts, there are differences or "gaps" in (digital) health literacy depending on age and social status. This was also made clear by Dr Alexander May, who as a practising doctor is himself frequently in contact with the target group of patients. In his opinion, it makes a huge difference whether one starts using digital tools already in childhood or not, which thus creates different starting points with regard to the competences mentioned. At the same time, Prof. Dr. Michael Doh mentioned that demographic factors should not be seen as stand-alone explanatory variables. For example, with regard to the group of older people, individual biographies and technical experiences as well as socio-psychological and gerontological effects would also play an important role.

With regard to information skills on the internet, the above-mentioned study data and the citizens we interviewed also reveal a recognisable knowledge gap. All interviewees stated that they first googled for health information as soon as they needed it. None of the interviewees stated that they used health portals or other statutory or public information services. At the same time, however, some of the citizens said that they knew that health information on the internet should not be taken completely seriously. One interviewee said: "if you Google three or four times, you definitely have cancer".

This opinion was also shared by the other interviewees, who considered a lot of information on the internet to be rather dubious and questionable. In this context, it would be important to use different sources and to check by whom the information is provided (institutes, government organisations, medical associations, etc.) and then decide to what extent the information read there is reliable. However, the interviewees still see discussions with medical experts as the most important source of information.

In this context, the internet was given a mixed assessment with regard to its usefulness as a source of information by the citizens surveyed. However, with the addition of the above-mentioned study by the Initiative D21, it becomes clear that most people in Germany, depending on their level of education and age, are now able to conduct internet research and use various sources for verification. At the same time, however, also with regard to the study by the University of Bielefeld, there is a gap in terms of information and data skills in the health sector, as also our respondents did not really know where else to look for health information outside of Google.

A large knowledge gap is also revealed with regard to existing online health services. None of the interviewees stated that they used an online portal or other digital services outside of their own health insurance app. One reason for this could be that none of the interviewees, regardless of age group, knew about the digital offer of the electronic patient file or the German health portal, for example. At the same time, this was one of the biggest points of criticism from the interviewed expert Prof. Dr. Michael Doh, who classified the lack of education and dissemination of existing digital services such as the ePA as an obstacle to the broad implementation of digital health services.

At the same time, the above-mentioned problem seems to be connected with another knowledge gap in the area of health data competences. None of the respondents knew exactly where their medical data was stored and all of them could only guess that it must be stored at GPs and health insurance companies. The same was true with regard to the question of who can access their data and how personal data can be requested and deleted. In this context, Dr. Alexander May also stated that there was a lack of information for patients. Further education would be needed to introduce many people to digital services. In this context, a lack of health information and data competence is possibly related to a lack of competence about existing digital health services.

The interviewees also stated that information in doctors' reports and medical documents was sometimes difficult to understand. This was mentioned especially with regard to specialists and laboratory tests, where technical terms and abbreviations that were difficult to understand were often used. It was often necessary for our interviewees to google individual terms. An interviewed citizen, who herself works in the medical field, stated that such information is usually not understandable for "ordinary consumers". This is also in line with the above-mentioned study results of the University of Bielefeld, which identifies the assessment of health information as a problem area.

It is also interesting that although the level of knowledge of the respondents was not really up to date, regardless of the level of education, all respondents use or have used an app of their health insurance company as well as calendar reminders for appointments in their mobile phones. This suggests that the respondents at least actually use the help offers they are aware of and consider helpful. This is also in line with Dr Michael Doh's statements from the University of Freiburg. In his eyes, the gap described also exists due to the fact that existing digital offers in the health sector, such as the ePA, do not receive sufficient promotion or introduction.

For example, this service is largely unknown in Germany, despite being in operation for almost two years now. Moreover, the use of the service is also very complicated, since the necessary documents such as findings, treatment documents, etc. have to be entered by the insured persons themselves.

4.2 Identified Learning needs and demands of the target groups

Based on the literature used so far and the interviews with citizens and experts, the challenges and problems within the health system are wide-ranging. The experts interviewed see various reasons why existing services such as the ePA have not yet been used sufficiently. In this context, the strong technical variance of the existing offers was mentioned, which makes constant updating and adaptation to current conditions necessary. This makes the development of digital health services more difficult, since even in short periods of time, such as one year, significant technical innovations can occur.

At the same time, experts mentioned that many people probably had a low self-assessment of their digital health and technology skills, so that many people did not use such services out of shame or fear of data misuse. Other groups of people simply lack such skills, which ultimately has a strong negative influence on their use.

However, there would also be groups of people who simply do not want to know everything about their own health, or for whom it is difficult to break out of old habits regarding the health services they use. These statements by the interviewed experts coincide with the findings of the study by the University of Bielefeld, in which the general level of health literacy in Germany is classified as rather low. In addition, there are not insignificant proportions of people who are less likely to want to know about all the parameters of their health, especially within the groups of people with a low social status and a low level of education.

As essential needs the experts mentioned the importance of tailor-made and adapted information and learning offers for different groups of people. Thus, it is important to provide information in different languages and as barrier-free as possible and to address all the different target groups of the learning offer.

At the same time, it was mentioned that a better networking of different existing solutions and offers in the area of health data and literacy was needed. As an example, solutions from the area of care management could be linked with those of discharge management and thus create significantly more synergies.

At the same time, there would currently exist a high demand for digital solutions that could be used by all people in a field or a group of actors in the same way, e.g. an app that can be used by all medical professionals throughout Germany. This from the perspective of Dr Michael Doh would also make it much easier and more effective to explain and communicate technical innovations and functions. At the same time, as already mentioned, the experts spoke out in favour of more information for patients. In this context, Dr Alexander May stated that information campaigns and political marketing would have to be used more intensively for this purpose.

In view of the interviews and scientific data gathered, it can therefore be seen that people in Germany have learning needs in several competence areas listed here. These include digital health competencies in general, which includes the ability to use digital health services and information as well as their evaluation. Although all respondents within our small sample used a health app, statistically only 21% of the population do so [14].

At the same time, none of the respondents used other online health services. Therefore, another important learning need is represented by education about existing information services such as the ePA or the German health portal and their use. In this context, there is also a learning need for all age groups to be able to understand and correctly evaluate online information as well as information from doctors' reports, which a novel learning offer in the TRIO project must increasingly address.

In addition to teaching (digital) health skills, there is also a need for physical access to and use of digital devices. The citizens and Prof. Dr Nadine Konopik mentioned that socially disadvantaged groups such as older people or people with a migration background and language barriers need to be better supported by offers adapted to them. In this context, Dr Konopik mentioned, for example, support in accessing digital devices as well as adapted local support services in different languages and for older people.

5. Examples of good practices and educational training offers

In Germany, there are already various online information services. These include the National Health Portal, which has been providing neutral and scientifically proven medical information in an online portal since September 2020. This information includes information on the digital health system, information on care topics, recommendations for a healthy life and general information on specific diseases. The portal works together with research institutes to ensure the high quality and safety of the information [24].

Likewise, two websites for health information were developed within a funded research project of the Ministry of Justice and Consumer Protection in cooperation with the University of Cologne.

These aim to teach the target groups of young people and middle-aged adults skills in dealing with online health information. The websites are very similar in structure and cover many important areas of competence such as dealing with search engines and many more. It is noticeable that the two websites differ almost only in their visual design in order to address the two age groups more directly with the information they offer [25].

A learning offer in presence can be found within the Saxony-Anhalt state strategy for health (health literacy). As part of a research project funded by the Federal Ministry of Education and Research, health skills have been taught through lectures, workshops and publications since 2018. For this purpose, competence pilots were also trained in the course of the project, who are to impart the competences mentioned in their professions or voluntary activities to the various target groups [26].

Also in the area of promoting (digital) health skills, there are already projects or training opportunities in Germany. For example, the Stiftung Gesundheitswissen (Health Knowledge Foundation) launched the initiative "Pausenlos gesund" (Healthy without breaks) in 2018. Within this framework, children and young people are to be familiarised with the aforementioned areas of competence already at school by providing teaching materials in eight different areas (e.g. how to correctly classify information on Google) for teachers. This also includes the interactive game *Gesundweiser*, which conveys the contents in a playful form [27].

There are already numerous offers and training courses in Germany for teaching digital skills in general. Even those that are aimed at specific target groups such as senior citizens or migrants. Examples of this are the digital mentors in Leipzig, where volunteers impart digital knowledge to older people in a personal, direct way [28].

6. Suggested input for TRIO training and education

The questions regarding the learning platform show that all respondents, regardless of their age group, prefer a mixture of different learning contents. It was noted that too much text on websites is often off-putting and very tedious, which is why a mixture with learning videos was mentioned as desirable by many of the respondents. In this context, several respondents mentioned that videos and visualised content were generally easier to remember. Explainer videos or tutorials should also be provided with subtitles so that all target groups could easily take in the information. In addition, citizens and experts suggested that an easy-to-use overview page was essential. A search function on the learning platform as well as clearly defined topics and headings were important so that all target groups could reach their goal with just a few clicks. A chat function was also mentioned as a possible solution for this, so that people with operating problems would always have a direct offer of help.

Dr. Alexander May also mentioned the idea of possibly being able to make direct appointments with doctors in the vicinity via the learning platform. The expert Dr. Konopik also mentioned that the learning platform should be made available in different languages and that easy-to-use language and many symbols should be used. In addition, the site should be designed based on the needs of the socio-economically disadvantaged groups mentioned, by identifying the greatest obstacles of the target groups mentioned. Dr. Michael Doh also pointed to a glossary of important terms as a helpful tool for the creation of the learning platform. From there, it would also be possible to refer to further websites and learning opportunities. With regard to the existence of various such information offers, Dr. Michael Doh also pleaded for a stronger networking of existing services in order not to create too many confusing parallel structures, but rather more synergies between existing offers. Finally, he stated that in terms of sustainable learning success, the peer-to-peer method is currently the best way to further educate people who are uneducated or uncertain about their digital health skills. Therefore, the informal learning path would be most suitable for this.

7. Relevant Stakeholders and potential cooperation partners

Key stakeholders include all those people who work in the field of health management or in the field of health care. This could include, for example, doctors who could refer to the learning platform in their work or people who come into contact with different target groups professionally in the social sector such as in neighbourhood offices or other public facilities.

In the same way, the learning platform could be used by public health services such as rehabilitation centres, pharmacies or other public bodies and brought to the attention of the general public.

With regard to the broadest possible usability of the learning offer, cooperation with organisations for refugees or for people with a migration background as well as with senior citizens' associations such as the BAGSO would also make sense, as this would be the best way to include the needs of all target groups in the design of the learning platform. Dr. Michael Doh also mentioned that cooperation with adult education centres would be a first sensible step to be able to disseminate the learning platform across different municipalities and target groups.

In addition, the operators behind the existing digital health solutions are also important stakeholders. The ePA or health insurance apps could be presented and explained within the learning platform and thus possibly also increase their usage figures. From the point of view of the experts interviewed, stronger synergies could also be created through the connection of already existing offers and solutions. Furthermore, networking with other project consortia that have already carried out similar projects or are currently doing so, such as the State Strategy for Health Literacy in Lower Saxony, could be useful. In this way, trained facilitators/lots* could use the platform as a teaching tool and thus further broaden its impact.

8. Quotes from Interviewees

"If you Google three to four times, you definitely end up with cancer." (Citizen, 43)

When asked if she would use a learning platform:

"Sure, that way you would at least know where to look something up, especially when it comes to health." (Citizen, 56)

"I wouldn't have an operation just on the basis of information from the internet." (Citizen, 37)

"It takes certain soft skills to find your way through the flood of information." (Citizen, 27)

"Some patients think they are in the right professionally because they have found information on the internet". (Dr. Alexander May)

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10. Annex – Interview Questions

Leitfragen für Interviews mit Bürger:innen

Einführung in das TRIO Projekt:

Unser Gesundheitssystem unterliegt starken Digitalisierungsprozessen, aber nicht jeder hat die digitalen Fähigkeiten, die Kenntnisse über Gesundheitsinformationen oder die Kenntnisse über Daten, um mit diesem Wandel Schritt zu halten. Das TRIO-Projekt soll den Menschen helfen, diese drei Fähigkeiten zu verbessern, damit das Gesundheitssystem für alle zugänglich bleibt. Zu diesem Zweck entwickeln wir mehrere Instrumente: ein Handbuch, ein Toolkit, ein Diskussionspapier und eine Online-Lernplattform für die Erwachsenenbildung. Doch zunächst müssen wir herausfinden, wo genau die Lücken und Bedürfnisse liegen und wie wir unsere Instrumente am besten auf diese Bedürfnisse abstimmen können. Zu diesem Zweck befragen wir Menschen aus verschiedenen Altersgruppen und mit unterschiedlichem Bildungshintergrund sowie Fachleute aus dem Gesundheitswesen und der Politik.

Nutzung von Daten:

Das Interview wird zunächst zusammengefasst und dann zur Revision an Sie zurückgeschickt. Die Zusammenfassung wird als Informationsquelle in unserem nationalen Bericht verwendet, wird aber nicht wörtlich transkribiert. Die von Ihnen gegebenen Antworten sind völlig anonym. Wir können Sie fragen, ob wir ein Zitat in den Bericht aufnehmen dürfen, aber Ihr Name wird nicht genannt. Stattdessen werden wir alle Befragten nach Alter und Bildungsniveau gruppieren, und alle Zitate werden als solche gekennzeichnet.

Alter: ...

Geschlecht: ...

Geburtsland: ...

Bildungsniveau (ISCED 2011 level 0-8): ... (partners search for the allocation of their national education programs into ISCED 2011)

Professioneller/ ehrenamtlicher Hintergrund: ...

- Q1** Glauben Sie, dass die medizinische Grundversorgung in Ihrem Land für alle gleichermaßen zugänglich ist? Sowohl in finanzieller Hinsicht als auch in Bezug auf die körperlichen und geistigen Fähigkeiten.
- Q2** Wissen Sie, wie Sie im Internet nach Gesundheitsinformationen suchen können? Wenn ja, wie würden Sie das tun?
- Q3** Wie können Sie feststellen, ob die Gesundheitsinformationen, die Sie im Internet finden, korrekt sind (und nicht falsch oder irreführend)?
- Q4** Wie nützlich finden Sie das Internet, um Entscheidungen bezüglich Ihrer Gesundheit zu treffen?
- Q5** Nutzen Sie ein medizinisches Online-Portal wie das deutsche Gesundheitsportal? Wenn ja, warum? Wenn nein, warum nicht?
- Q6** Wissen Sie wo Ihre medizinischen Gesundheitsdaten gespeichert werden? Wenn ja, wo?
- Q7** Wissen Sie, wer Zugang zu Ihren medizinischen Daten hat? Wenn ja, wer?
- Q8** Finden Sie, dass Ihre medizinische Akte leicht zu verstehen ist? Haben Sie zum Beispiel Schwierigkeiten, medizinische Dokumente wie Untersuchungsberichte oder Bluttests zu lesen? Verstehen Sie die Anweisungen zur Medikamentendosierung?
- Q9** Wissen Sie, ob und wie Sie auf Ihre Krankenakte zugreifen und Änderungen an deren Inhalt und Zugänglichkeit vornehmen können? Wissen Sie zum Beispiel, wie Sie vorgehen müssen, wenn Sie einen Teil Ihrer Krankengeschichte löschen oder sicherstellen möchten, dass andere medizinische Fachkräfte keinen Zugang zu ihr haben?
- Q10** Verwenden Sie digitale Hilfsmittel, um Ihre Arzttermine oder Ihren Medikamentenplan im Auge zu behalten, z. B. einen Telefonkalender oder einen Alarm? Wenn ja, finden Sie sie einfach zu benutzen? Wenn nicht, wissen Sie, wo Sie diese finden und wie Sie sie nutzen können?
- Q11** Verwenden Sie eine Anwendung, die Ihnen hilft, Ihre Gesundheit zu überwachen, z. B. Ihr Gewicht, Ihren Blutdruck oder Ihren Blutzuckerspiegel zu kontrollieren? Benutzen Sie eine solche Anwendung? Wenn ja, welche Funktion hat sie?

Qop1 Ist es üblich, dass Sie bei einer medizinischen Untersuchung aufgefordert werden, ein Dokument mit Ihren persönlichen Daten zu unterschreiben? Können Sie das Dokument lesen und verstehen? [Optional, falls für Ihr Land zutreffend]

Qop2 Sind Sie in der Lage, dem Arzt Ihre Krankengeschichte zu schildern? Ist es notwendig, Ihre früheren Untersuchungen mitzubringen? [fakultative Frage, falls für Ihr Land zutreffend]

Die folgenden Fragen beziehen sich insbesondere auf das TRIO-Projekt

Q12 Wären Sie daran interessiert, eine Online-Lernplattform und/oder ein Handbuch zu nutzen, um Ihre digitalen Gesundheitskompetenzen zu verbessern? Wenn ja, warum? Wenn nein, warum nicht?

Q13 Wenn Sie eine Online-Lernplattform nutzen würden, welche Form von Informationen (z. B. Erklärungstexte, Bilder, Videos, Übungen usw.) wäre für Sie am hilfreichsten?

Q14 Was wäre Ihrer Meinung nach ein guter Weg, um Menschen, z. B. Menschen mit sozioökonomischen oder gesundheitlichen Problemen oder Menschen im höheren Alter, zur Teilnahme an einer Schulung zur Verbesserung ihrer digitalen Gesundheit und Datenkompetenz zu ermutigen?

Möchten Sie sich auch in Zukunft an dem Projekt beteiligen? Wären Sie an einer Teilnahme an der Co-Creation-Sitzung interessiert?

Leitfragen für Interviews mit Expert:innen

Einführung in das TRIO Projekt:

Unser Gesundheitssystem unterliegt starken Digitalisierungsprozessen, aber nicht jeder hat die digitalen Fähigkeiten, die Kenntnisse über Gesundheitsinformationen oder die Kenntnisse über Daten, um mit diesem Wandel Schritt zu halten. Das TRIO-Projekt soll den Menschen helfen, diese drei Fähigkeiten zu verbessern, damit das Gesundheitssystem für alle zugänglich bleibt. Zu diesem Zweck entwickeln wir mehrere Instrumente: ein Handbuch, ein Toolkit, ein Diskussionspapier und eine Online-Lernplattform für die Erwachsenenbildung. Doch zunächst

müssen wir herausfinden, wo genau die Lücken und Bedürfnisse liegen und wie wir unsere Instrumente am besten auf diese Bedürfnisse abstimmen können. Zu diesem Zweck befragen wir Menschen aus verschiedenen Altersgruppen und mit unterschiedlichem Bildungshintergrund sowie Fachleute aus dem Gesundheitswesen und der Politik.

Nutzung von Daten:

Das Interview wird zunächst zusammengefasst und dann zur Revision an Sie zurückgeschickt. Die Zusammenfassung wird als Informationsquelle in unserem nationalen Bericht verwendet, wird aber nicht wörtlich transkribiert. Die von Ihnen gegebenen Antworten sind völlig anonym. Wir können Sie fragen, ob wir ein Zitat in den Bericht aufnehmen dürfen, aber Ihr Name wird nicht genannt. Stattdessen werden wir alle Befragten nach Alter und Bildungsniveau gruppieren, und alle Zitate werden als solche gekennzeichnet.

Organisation: ...

Beruflicher Hintergrund: ...

- Q1** Begegnen Sie in Ihrem Beruf vielen Menschen mit geringen Kenntnissen in den Bereichen Digital-, Gesundheits- oder Datenkompetenz?
- Q2** Wenn ja, gibt es sozioökonomische oder demografische Variablen, die Ihrer Meinung nach damit zusammenhängen?
- Q3** Welche Vorteile und welche Probleme ergeben sich Ihrer Meinung nach aus der Digitalisierung des Gesundheitswesens?
- Q4** Nutzen Sie selbst Online-Gesundheitstools, wie Gesundheitsportale, medizinische Websites oder Online-Unterstützung im Gesundheitsbereich?
- Q5** Was sind Ihrer Meinung nach die wichtigsten digitalen Gesundheitswerkzeuge für die Menschen? Beispiele: Medikamentenerinnerungen auf Handys? Ja oder nein. Veröffentlichung von medizinischen Überwachungsdaten wie Gewicht, Blutdruck und Zuckerwerte? Ja oder nein. Zugriff auf Apothekenrezepte? Ja oder nein.
- Q6** Welche Online-Gesundheitsinstrumente fehlen oder sind nicht für alle zugänglich?

- Q7** Was sind Ihrer Meinung nach die Haupthindernisse, die Menschen davon abhalten, digitale Gesundheitswerkzeuge zu nutzen?
- Q8** Wie können wir die politische Ebene nutzen, um einer größeren Zahl von Menschen den Zugang zu Online-Gesundheitsinformationen zu ermöglichen?
- Q9** Glauben Sie, dass es den Menschen bekannt ist, wo ihre medizinischen Daten gespeichert werden? Wissen Sie selbst, wo Ihre medizinischen Daten gespeichert sind?
- Q10** Halten Sie es für wichtig, dass die Menschen mithilfe einer Online-Plattform Einblick in ihre eigene Krankengeschichte erhalten? Glauben Sie, dass dies einfach zu nutzen wäre?

Die folgenden Fragen beziehen sich insbesondere auf das TRIO-Projekt

- Q11** Welche Informationen sollte die TRIO Lernplattform enthalten, damit sie für die Menschen nützlich ist? Und welche Form von Informationen (z.B. Erklärungstexte, Bilder, Videos, Übungen, etc.) wäre am hilfreichsten?
- Q12** Was sollte eine Online-Lernplattform enthalten, damit sie für Menschen mit geringeren Möglichkeiten (z. B. Menschen mit sozioökonomischen oder gesundheitlichen Problemen oder Menschen im höheren Alter) attraktiver ist? Wie können wir Menschen, die (z. B. aufgrund finanzieller oder gesundheitlicher Probleme) weniger Möglichkeiten haben, die E-Learning-Plattformen zu nutzen, entgegenkommen? Was wird für sie benötigt?
- Q13** Wie können wir Menschen mit geringen eHealth-Kenntnissen zur Teilnahme an einer Online-Lernplattform motivieren?
- Q14** Haben Sie Ideen oder kennen Sie inspirierende Beispiele für einen besseren Zugang zu und ein besseres Verständnis von digitalen Gesundheitsdaten?

Möchten Sie sich auch in Zukunft an dem Projekt beteiligen? Wären Sie an einer Teilnahme an der Co-Creation-Sitzung interessiert?