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# Digitization in health-related self-help – Results of an online survey among self-help organizations in Germany

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## Abstract

**Background:** Nowadays, much hope and expectations are associated with digitization in the health sector. The digital change also affects health-related self-help. A nationwide survey of self-help organizations (SHOs) aimed to show chances and limitations in the use of interactive IT tools like webforums, online meetings or social media as well as digital infrastructures for their organizational management. In this survey, we also determined whether SHO staff themselves have support and qualification needs with regard to this topic.

**Design:** The online survey was conducted between 14 November and 8 December 2019, i.e., immediately before the outbreak of the Covid-19 pandemic. The questionnaire consisted of 50 questions consisting of 180 single items which could be answered in 30–40 min. After two reminder letters, 119 questionnaires of the SHOs were gathered and analysed.

**Results:** SHOs already have a lot of experience with digital media/tools (e.g., own homepage, social media, cloud computing). Some tools are attested a "high" or "very high" benefit by more than 80% of users. Perceived benefits, however, are also facing a number of problems, ranging from lack of resources to data protection issues. Despite, or even because of the limits of digitization, there is great desire and need for support and further training in SHOs (and self-help groups).

**Conclusions:** At many points in the survey it was shown that digital media can be a useful extension of "traditional" collective self-help. Taking into account the risks and limitations associated with digital tools, SHOs can be central stakeholders in digitization in health-related self-help.

**Patient or Public Contribution:** The study was financially supported by the Federal Ministry of Health, Germany. A detailed representation of the results is publicly available at: https://www.uke.de/dish.

## Keywords

Digitization, social media, self-help, mutual aid, support groups

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## Introduction

There are many hopes and expectations associated with digitization in the health sector today. The digital change affects not only medical care, but also non-clinical fields of action such as information transfer.[1] Voluntary patient and self-help organizations (SHOs) and their members as well as their associated self-help groups (SHGs) have long been important players in the German digital health

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care landscape.[2] Meanwhile, SHOs have started to digitize their offer of information, to store their data digitally, some even develop digital patient registers for research purposes.[3, 4] In addition to "traditional" SHGs, where people with the same (health) problem meet in person, IT-based forms of mutual aid are developing. These can be online forums, chat forums, Facebook groups or similar forms of internet-based exchange (so-called virtual self-help). While the members of traditional SHGs are – or better said "were" – not in need of IT skills, online-based mutual aid requires at least some basic computer or smartphone competencies.

Many representatives of self-help associations see the various possibilities of digital change not only as a chance, but also as a challenge. On the one hand, and as in any other institution, organization or enterprise, digitization makes self-help-related work in communication, organization and public relations considerably easier and more efficient. Communication is becoming much faster and more direct, the reach is increasing through e-mailing and other media tools – especially if electronic address databases are used – information is both easier gathered and wider spreaded, and public perception becomes greater. Digitization also has cost-reducing potential compared to older forms of communication and public relations, especially those associated with postal delivery or high printing costs for flyers and broshures. On the other hand, the design of digitization is associated with high requirements, of which the procurement and provision of technical infrastructure – apart from the associated costs – represent a rather minor problem. The technical and liability aspects of digitization are of particular concern.[5]

Against this background, the aims of our study were to find out:

1. How is the status of digitization in health-related SHOs, which approaches do exist and, if applicable, do they delop or run specific digital projects?
2. Do leaders of SHOs see digitization as a necessity, chance and progression, or do they feel burdened and overloaded with associated requirements, demands and possible risks?
3. Which needs and what kind of support do SHOs see for both themselves and their associated SHGs?

In order to provide self-help with a guideline for the design of current and future digital applications, the project should make recommendations for the future development of health-related self-help in the field of digitization. These recommendations for action are aimed at the public, but in particular at all those active in self-help (mutual aid) as well as at the sponsors of health-related self-help in Germany, i.e., primarily the health insurance funds. The recommendations are available online (https://www.uke.de/dish).

## Methods

The aim and the framework of the study were predefined in the tender text of the Federal Ministry of Health as the sponsor of this study. After we were awarded the contract by the Ministry, we developed first concrete objectives and questions as well as the operationalization of the different dimensions in this field by means of a literature review and brainstorming within the research team. In the next step, we conducted focussed interviews with 11 representatives of SHOs, self-help clearing houses, umbrella organizations of self-help and the National Clearing House for the Encouragement and Support of Self-Help Groups (NAKOS). Further nine self-help representatives participated via a short online survey with 10 open questions. The aim of this preliminary study was to develop a questionnaire for self-help organizations and self-help online associations that would capture experiences, assessments and needs as concretely as possible.

The first drafts of the questionnaire were circulated between and commented by all persons involved as mentioned above. The finalized questionnaire comprised 50 questions divided into approximately 180 items, and could be answered in 30–40 min, depending on experience and relevance. The SHO representatives were also given the opportunity to freely comment on the individual topics in the questionnaire. The nationwide online survey among SHOs took place from 14 November to 8 December 2019, just before the Covid-19 pandemic outbreak.

With the help of the so-called GREEN ADDRESSES of NAKOS (www.nakos.de/adressen/gruen), a register of almost all federal SHOs in Germany, 287 e-mail invitations were sent to SHOs, including 37 representatives of "pure" self-help internet forums. As part of the online survey, the questionnaire could be downloaded as a PDF file for preview. In order to also cover the state level of SHOs, the persons addressed were asked to pass on the access data for the online survey to their state representatives (if available). After two reminders, which should underline the scientific seriousness and the aim of the survey, n = 119 SHOs replied. The federal SHOs (without internet forums) participated with n = 89, or 35.6% of 250. This is an acceptable response rate – measured by the questions and the scope of the study. In contrast, representatives of online forums only participated in the study with 14.7% (n = 5 out of 37).

## Results

The results of the survey are summarized below according to the six topic blocks of the questionnaire. Missing values (e.g., "don't know", no information) were excluded from the analysis in accordance with the GESIS Leibniz Institute for the Social Sciences guidelines.[6] We also integrated quotes from the free answers for better understanding and illustration.

## General information

The study represents the entire range of topics of the SHOs and umbrella organizations that exist in Germany, particularly those that operate nationwide. Almost all institutions work on problems with chronic illnesses and disabilities. When asked about the main focus of their activities, 29% of the SHOs state "disabilities", 24% "diseases of the skeleton, muscles or connective tissue" and each 23% "internal" and "neurological diseases" as the most common topics. Nevertheless, a clear assignment in the area of self-help is not always possible, since health problems often occur in combination and are associated with social and psychological stress.

On average, the SHOs that participated in the study existed for 25 years. About half of them (52%) were only founded after 1996. They have up to 49,000 natural persons as members (median: 297). On average, the SHOs, apart from one "outlier", are divided into 16 member- or sub-organizations and supervise around 55 of their own self-help groups. The number of full-time employees and full-time positions varies widely depending on the organization: 43% of the SHOs do not have a single full-time employee, approximately 36% one to three professional people to support them and 21% more than three full-time employees.

## Current status of digitization

The first focus of the survey was on the current status of digitization in self-help. Respondents should indicate which digital media and tools (e.g., homepage, social media, apps or clouds) are used in their SHO and how often. We roughly differentiated between three primary uses: Media/Tools for (a) external communication, (b) internal communication and (c) administration and/or research.

Figure 1 shows that almost all SHOs use an own homepage for public relations work. The homepages are addressing interested people, specifically those who are affected by the SHO's relevant indication area or topic. In addition, it can be seen that a large number of organizations also use social media such as Facebook (67%), messenger services (e.g., WhatsApp) (53%) and online newsletters (48%) at least partially for these purposes. These tools are mainly used by SHO or SHG members. The Web 2.0 trend, i.e., the use of internet applications beyond former IT, which are characterized by participation of the users, has thus long arrived in the self-help community.

Further IT tools such as cloud systems for storing and jointly processing files (e.g., Dropbox, Google Drive) or appointment coordination services (e.g., Doodle) help to facilitate and optimize the internal organizational work and its processes. These are mostly used by around 60% of the SHOs. Net meeting services (e.g., Skype, Circuit) are used by almost half of the organizations surveyed, albeit only 17% intensively.

Significantly less common than web and messenger services are IT systems that are used for more complex administration and/or research (the common office applications are excluded here as an essential standard). These include customer management systems (e.g., Microsoft Dynamics, Systemanalyse und Programmentwicklung [SAP] customer relationship management [CRM]) or project management systems (e.g., Microsoft Planner, Trello, Basecamp) with a penetration rate of less than 20%. In this area, IT tools, which were developed for online (member) surveys (44%) and for data analysis to evaluate their own SHO (32%), are most likely to be used.

In an open question, the SHOs were able to state which digital services would be of greatest benefit to them and why. The vast majority of responses were received on the own website in order to reach those affected and to pass on information on illness and support. *"The homepage offers best accessibility for members and especially non-members/potential new members."* (CEO of an SHO on rheumatism). Facebook and other social media services (e.g., WhatsApp) were also praised for the possibility of exchanging information and experiences, but less often due to the number of active users. *"We run our group where people are anyway. For many, Facebook is part of their world. Traditional self-help should not make the mistake of ignoring people's lives and needs. Social media is a part of it. Facebook is our best aquiese tool."* (CEO of an SHO for families with disabled children). The SHOs associated less or no benefit with digital tools that are hardly used (e.g., chat, online forums), which are too complex to control or too difficult to use (e.g., Instagram, Cloud).

Asked more specifically, the SHO's own *homepage* is mainly used to provide links to other organizations (79%), self-help groups (68%) and online forums (53%). To make the homepage user-friendly, two-thirds of the organizations use a "responsive" design, i.e., the graphics are optimized for smartphone or tablet use. One-third of the SHOs also enrich their websites with images and explanatory videos. However, only 9% of all websites have a seal of approval or certificate. The annual costs for maintaining the homepage, i.e., expenses for web hosting, software, server, IT service by external providers, amount to 1826 Euros (EUR) on average. Costs for full-time or volunteer staff within the organization are not included here. However, this seems to be worthwhile from the point of view of the SHO representatives interviewed, as the homepages are generally considered to be of great benefit to the SHO (87% "very high" or "high"). *"The homepage incl. forum is the only reference work for us in German."* (Chair of an SHO on ectdermal dysplasia).

Among the reasons for using *social media*, the possibility of referring to events, placing links to one's own or other

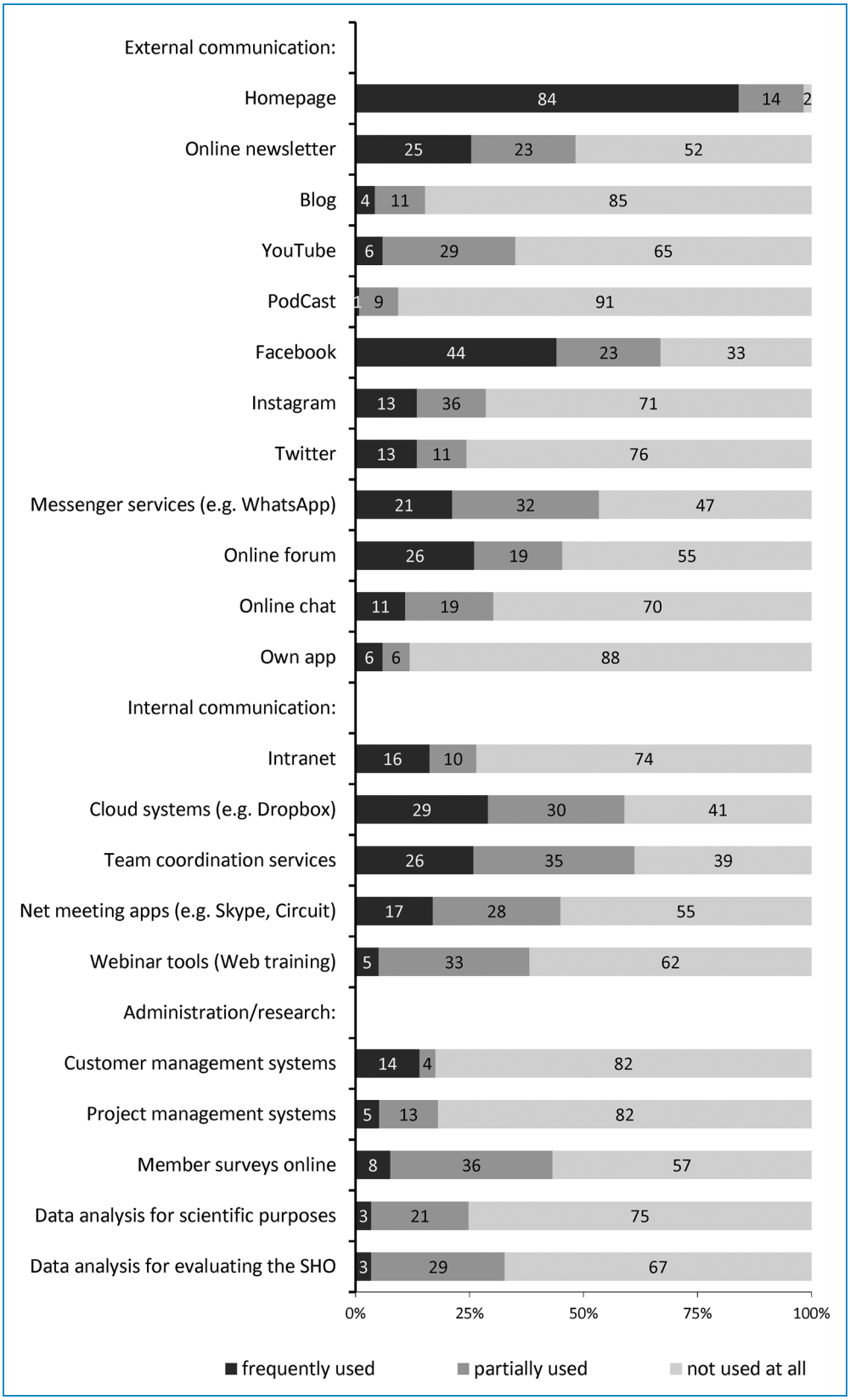


**Figure 1.** Use of digital technologies (in %; n = 114 to 119). SHO: self-help organization.

homepages and advertising for self-help dominate with more than 70% of the yes answers. This underlines the growing importance of social channels for public relations. But also other, more interactive motives are conceded by more than two-thirds of the SHOs: exchanging information about health problems and winning new members. The annual costs for the maintenance of these social media platforms (excluding costs for personnel within the organization) amount to 286 EUR on average. In order to update the media regularly, 56% of the SHOs need more than five hours per month. The benefit is not quite as high as on the homepage, but is still rated "high" or "very high" with 70%.

*Online forums* are offered by 45% of the SHOs. In most cases they are accompanied and regulated: there is moderation to control the discussions (87% of the SHOs with a forum), clear rules for communication (83%) and restricted access (e.g., only for registered users) (77%). *"The patient forum is used a lot and is the most frequented. Here, advice and exchange of experience can take place within the framework of self-help, and new findings from research can be compiled."* (Chair of an SHO on Tick-Borne diseases).

Less secured, however, is the financing, but possible advertising income or sponsoring seem to be a "no-go" for the SHO. And something else is striking: Not even every fifth organization has a quality certificate for the online forum. With an average of 1628 EUR per year, the costs for operating the online forum are almost as high as for maintaining the own homepage. In 62% of the SHOs, the time required for this is up to 10 hours per month, and a "high" or "very high" benefit is attested by 58%.

The majority (58%) of the few *app users* among the SHOs run an app that they developed in cooperation with another provider, followed by apps in cooperation with a provider (33%) and/or alone (21%). In most cases there is no financial support for this (even without advertising). About one-third of the app users use their own server for operation and offer their users the option of storing their own data. About 42% of SHOs with their own app also have a protected chat area. The development costs for the app averaged 12,714 EUR, the annual operating costs 1317 EUR. Regular updates of the administrative framework and content also require a relatively large amount of time (73% more than five hours a month). However, the financial and time expenditure seems to be worthwhile from the SHOs' point of view: the use of the app is rated as "high" or "very high" by 80%.

A look at the SHOs' equipment with IT infrastructure (hardware, software, network) does not show any "outdated landscape" compared to modern media/tools (Figure 2). Only 1% to 9% of those surveyed described their IT as rather outdated. Instead, networks (e.g., internet access, WLAN) and IT security (e.g., data security, virus protection) are technically up-to-date in more than two-thirds of the SHOs surveyed, according to their own assessment. In the case of software (e.g., MS Office, OS) the figure is still 59% and in the case of hardware (e.g., PC, mobile devices) it is 52%, according to their own assessment. Not surprisingly, the digital infrastructure of the large SHOs with a high annual budget is technically on a better level than that of the smaller SHOs. This is particularly true for IT security: 90% of the SHOs with an average annual budget of 200,000 EUR (upper quartile) are up-to-date, but only 58% of the SHOs with less than 3000 EUR (lower quartile). Similar – but less pronounced – are the differences between old organizations (founded before 1990) and young SHOs: young organizations founded after 2007 feel better equipped in hardware and software than older SHOs.

The majority of volunteers (61%) and/or external service providers (43%) are responsible for computers and digital infrastructure. A third of the SHOs also commission one or more of their own data protection specialists in accordance with the General Data Protection Regulation (GDPR). Only every fifth SHO (21%) relies on an external specialist for data protection, but almost half (46%) have no person at all for this task. In general, this also confirms the finding that SHOs with a large annual budget invest more in their IT equipment and security than smaller SHOs.

## Digitization expenses

Measured against their average annual budget of the past five years, the SHOs' costs for investments, maintenance and repair of the IT infrastructure amounted to approximately 18,800 of 229,000 EUR per year (5900 EUR in 2019). This corresponds to around 8% of the funds spent. In contrast, the average costs for IT consultancy and IT training were comparatively moderate at 1100 EUR per year (900 EUR in 2019) and "only" account for 0.5% of the average annual budget. Overall, this leads to an estimated IT investment rate of 9%.

Three-quarters (76%) of the surveyed SHOs finance their digital infrastructure and further training with membership fees, followed by donations (62%) and funds from the health and long-term care insurance funds (56%; Figure 3). Income from the public sector, foundations and – as can be expected from non-profit organizations – the private sector hardly play a role. Since the majority of the SHOs finance their IT expenses and running costs from the total budget, i.e., the sum of all revenues, the sources of income specified here primarily reflect the general funding without direct connection to IT funding; the SHOs have to prioritize their expenses: *"We don't really like spending money on this stuff. In any case, no money and no manpower is budgeted for these purposes in the annual budget. Otherwise we would have to reduce core*

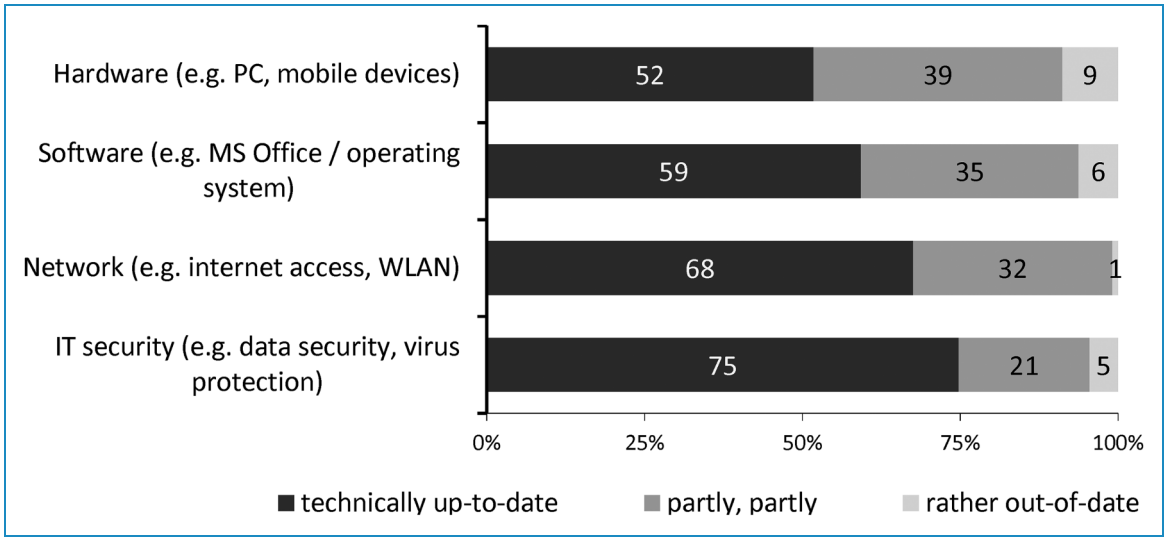


**Figure 2.** Status of the digital infrastructure (in %; n = 111 to 114). WLAN.

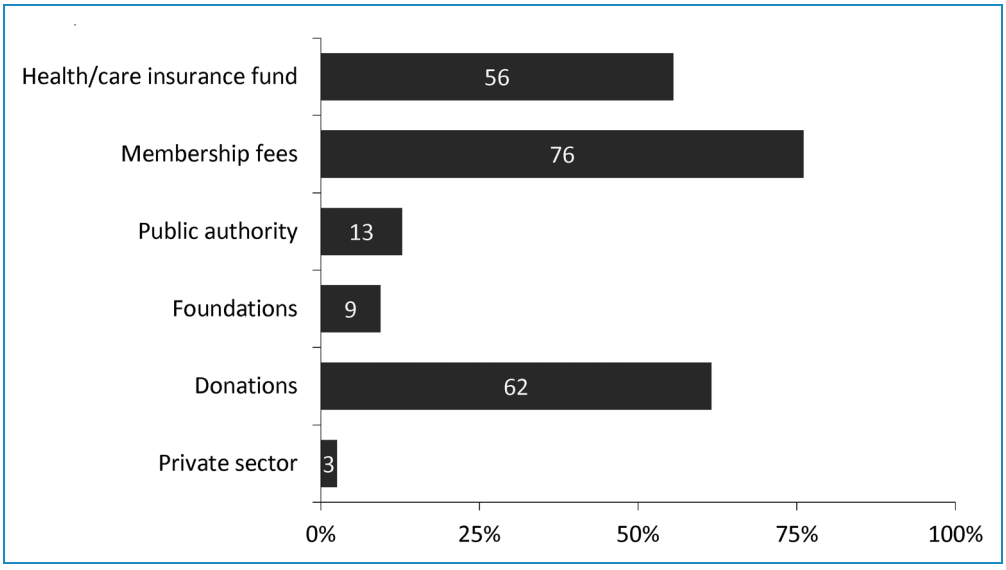


**Figure 3.** Financing of digital infrastructure and training (in %; multiple choices possible; n = 117).

*tasks."* (CEO of an SHO on obsessive-compulsive disorders).

In this context, self-help funding by health insurance companies in accordance with the German Social Code Book (§ 20 h SGB V) is of particular importance. About one-third (37%) of the surveyed SHOs had already been reimbursed the costs for their IT infrastructure (hardware) as part of the lump-sum funding; every fifth organization (22%) enjoyed corresponding project funding. SHOs received significantly less reimbursement for IT consulting and IT training, namely 11% (lump-sum funding) and 10% (project funding). In the free text data of the respondents, it is clear that the lump-sum funding generally flows into the operation of the office, to which, in general, the purchase of hardware (PC, tablet, etc.) also belongs, while the project funding is more used for the development of digital media (e.g., homepage) or IT training.

## *Importance and acceptance of digitization*

Given the use and usefulness of digital media/tools, it is not surprising that SHOs are not generally sceptical about digitization. On the contrary, almost everyone judges the changes due to digitization to be positive, one-third even "very positive". In comparison to the organization's core tasks, around three-quarters of those surveyed rated

digitization as "rather" or "very important". However, almost as many consider dealing with digital technologies to be "rather" or "very expensive". Nevertheless, 78% of the SHOs want to expand their digital services in the future.

The opportunities offered by digitization were part of a special topic in the study. There is particularly strong agreement that the public can be better informed through digital media, the exchange within the organization is accelerated (e.g., through emails, video conferences), and that members and target groups use digital tools more than five years ago (each with over 90% approval; see Figure 4). This is accompanied by an improvement in the image of self-help ("We are perceived as modern"), which, in the view of the majority of the SHOs, can have a positive effect on the recruitment of new, especially younger members, and the fulfilment of core tasks (e.g., public relations, information assignment, cooperation work).

Significantly less approval is given to statements regarding placement and coordination of volunteers planned with digital support (e.g., through online platforms, assistance apps), that participants are recruited for training and further education and/or online forums are a good supplement to personal group meetings (38% to 46% agreement). The expectation of opening up new fundraising channels (e.g., via online platforms, YouTube) is also viewed rather critically by the majority.

Some goals in the digital area can be better achieved with a partner than alone. The organizations surveyed would prefer to work with other SHOs when creating digital services, or already have joint digital tools. For just over half of the SHOs, however, self-help clearing houses, health professionals, universities or hospitals are also on the list of potential cooperation partners. Pure online self-help forums and/or private institutions/companies play a subordinate role in these considerations.

In addition to the opportunities, digitization presents SHOs with a number of possible challenges. More than 90% of the SHOs are of the opinion that purely digital services cannot replace face-to-face self-help on site, also with respect for the age and capacities of their members. *"The patients I want to support with my work are only computer-savvy up to a certain age."* (Chair of an SHO on vasculitis). More than 70% of the surveyed organizations lack time, money and personnel for digitization. Just as many also state that it is difficult to meet the data protection guidelines and the requirement to continuously update the administrative framework and content of the digital services. *"We would like to use more, but we are purely volunteers and our resources are limited, also because many of us are still actively caring."* (Coordinator of an SHO on family caregivers). Given these limits, many SHOs come to the conclusion that they are deliberately "analogue" in certain areas.

Concerning the variance in the pros and cons or the assessment of chances and opportunities of digitization, most often they argued that this would be due to different views and interests between the "young generation" and the "old generation". *"Young self-help, whose target group is the digital natives, often has a hard time establishing itself in old, dignified organisations* [due to] *the average age of the governing bodies and their adherence to old structures and offices."* (Representative of an SHO on kidney diseases). Several participants stated that the older board members would hinder the development and would not let younger representatives to invent their ideas. The main reason would be a perceived excessive demand to deal with these new technologies and the fear of not being able to cope with these challenges. *"Since it is difficult […] to find new, young, active members, the 'old hands' are overwhelmed with these tasks. Teaching them the new knowledge takes a long time and is made more difficult by reluctance."* (Chair of an SHO for parents with children in need of intensive care).

It is astonishing that not only the small SHOs lack the necessary resources for digitization, but also at least 8 out of 10 large organizations with an annual budget of 25,000 to 200,000 EUR. More than 60% of the SHOs with a budget of over 200,000 EUR say that they lack the necessary resources. The lack of resources for digitization is evidently not only the result of a limited overall budget and/or scepticism about digitization, but also an expression of a lack of priorities.

## Support self-help groups in digitization

We asked the SHOs surveyed in this study to assess the need for support in the SHG digitization process. The results showed that 77% to 91% of the SHOs see a high to very high need in all aspects. This is particularly pronounced in the handling of sensitive data (risks of online offers, advice on IT infrastructure and data protection). Nine out of 10 SHOs believe that they need to support the groups in this area. But the desire to promote the exchange among SHGs on the subject of digitization or to facilitate personal meetings for purely online SHGs also ranges at the top of the list of support offers.

Comparatively less relevant for almost a quarter of the SHOs is the provision of a protected self-help communication platform (e.g., an alternative to WhatsApp) and/or an overview of quality-tested online offers.

## Current SHO support needs

Questions were also asked about the importance of support for the own organization in order to work more effectively with digital technologies. According to Figure 5, almost all SHOs want funding for digitization measures, followed by

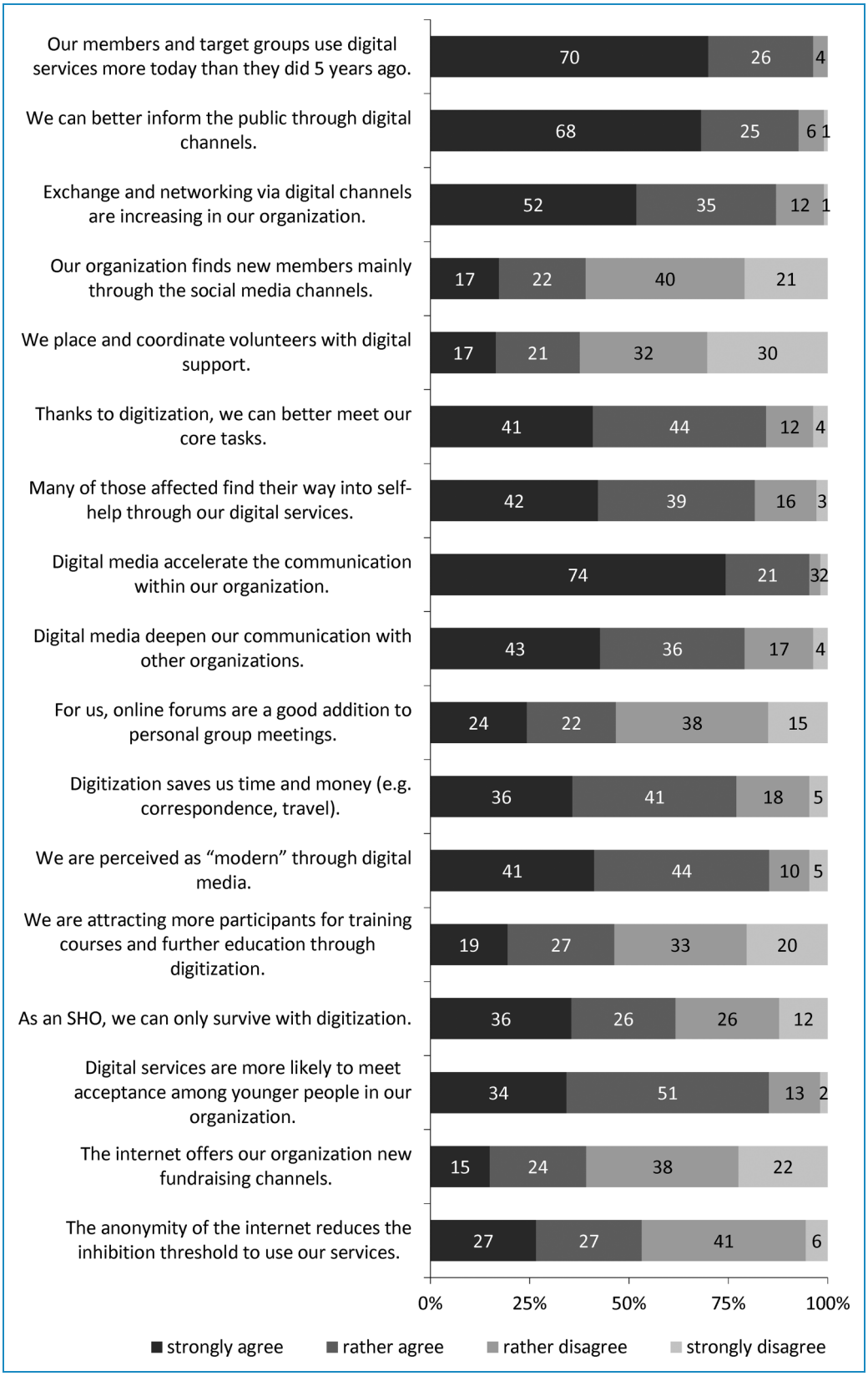


**Figure 4.** Opportunities and chances of digitization (in %; n = 107 to 110). SHO: self-help organization.

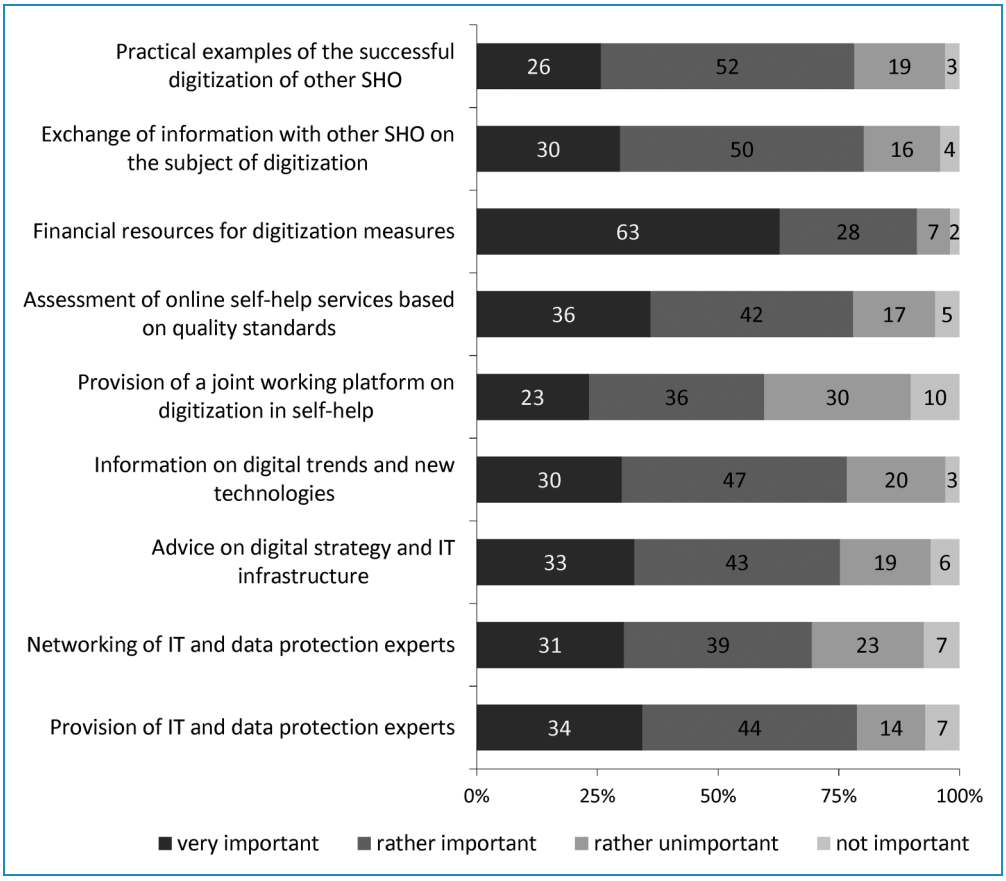


**Figure 5.** Importance of support for self-help organization (SHO) (in %; n = 95 to 103).

an exchange with other SHOs on the topic of digitization and the provision of IT and data protection experts. Also noteworthy, the provision of a joint self-help working platform is believed to be important by almost two-thirds (59%) of those surveyed.

In addition to material resources, the digitization of self-help also requires corresponding technical and social skills. SHOs see the greatest need for further training in dealing with data (data protection, data security, GDPR) (91%): *"I perceive a great deal of uncertainty associated with the complex design of the GDPR and cybercrime."* (Representative of an SHO on kidney diseases). This also holds true for knowledge of online tools (e.g., software, apps) (85%) and the quality of online communication (82%) – a result that applies somewhat more to large SHOs. However, more than half of those surveyed also consider training courses on digital hardware solutions (e.g., IT products, servers), internet advertising options and net meetings/webinars to be "rather" or "very important". This means that there is a more or less great need for further training in virtually all areas for many reasons such as *"We are an association with outdated technology, the average age is well over 70. At 63, I am almost the youngest and am trying to work my way into the IT material. But it's very difficult for me without a teacher."* (Chair of a hard of hearing association).

An open question on further support and/or training was answered by only five and four SHOs, respectively. This includes free qualification and the financing of the accessibility for digital services. *"I don't get any money, I do everything on a voluntary basis and I actually think it's unfair, although I like the idea of protecting our personal data."* (Chair of an SHO on vasculitis).

## Discussion

Many parts of the survey showed that the majority of the SHOs has experience with digital media/tools (e.g., own homepage, social media, cloud systems). For most users, these tools are a useful addition to the "traditional" self-help – this corresponds with the results of a study in the entire non-profit sector in Germany in 2017.[7] Following the model from an expertise on online self-help services (OSS), which is based on literature analyses and interviews with self-help experts,[8] the largest area of application of OSS is in asynchronous unidirectional input (Figure 6). This would be, for example, the homepage in Web 1.0 format without further interactive components, which

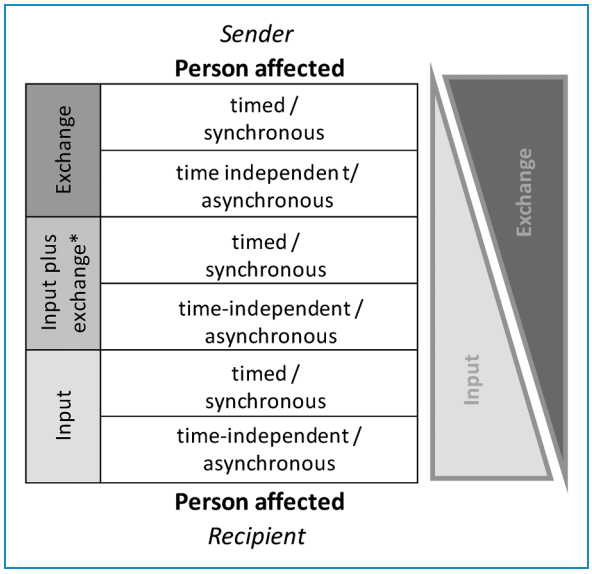


**Figure 6.** Definition of online self-help services (OSS).

holds true for practically all SHOs. Synchronous inputs with bi-directional or multidirectional communication – in other words: exchange – are probably rare, since information and explanatory videos or podcasts are much easier to upload and download, and are also more "customer-friendly" from the recipient's point of view because they can be called up at any time. About every third SHO enriches its homepage with such materials and media.

At level 2 (input plus exchange), OSS decreases significantly. This is where digital training events or so-called Webinars should be located. Webinars are mostly understood as further education events and are usually designed and organized as such. Meanwhile, they strongly mix with audio–video conference apps, which basically fulfil the same function. It is not only due to the Corona crisis that board and branch office members increasingly communicate more about this OSS meanwhile. In many SHOs, the board members and employees of the branch offices live far away from each other, so that this option is being used more and more frequently – as in almost all areas of social life.

Digital tools for administrative tasks (e.g., customer management or project management systems) are less common. It has become clear that many organizations have to catch up to terms of digital skills in order to make their organizational and office management more efficient by using appropriate hardware and software.

Simplified and pointed, we are dealing with two main application areas and target functions with regard to OSS in SHOs:

1. Information transfer (providing or sending information from SHO to members or the public)

   Digital technology opens up a wide range of options for the SHOs, which are very cost-effective compared to print media and postal transmissions. These are also highly appreciated and positively evaluated by the SHOs. First and foremost, these include the SHOs' own homepage and e-mailing. But social media is also used in particular as instrument for conveying information. This is – for example – where Facebook does the work.
2. Exchange (sharing information in a bi-directional interactive way)

   The exchange of information and experience, the fundamental principle of collective self-help, takes place at different levels with different OSS. Almost half of the SHOs surveyed have online forums and chats in their portfolios. These can be open or private. The open ones serve other affected persons who are looking for information and help to benefit from the experiences and tips of the peers and, if necessary, to ask questions themselves. The private ones, which to our knowledge are usually reserved for members only, offer a protected space in which they can feel more private and secure.

Today, two-and-a-half years after the survey, the results will most likely look significantly different. The internet-based tools driven by the Corona crisis, such as Microsoft Teams, Google Meet, Zoom, Cisco Webex, etc., are likely to have a disruptive effect on existing applications such as Adobe Connect, as they are easy to use, more than satisfy the basic requirements for Webinars and are technically largely stable (assuming sufficient internet bandwidth and performance of the digital end device). Here the synchronous multidirectional exchange is in the foreground, and it is not difficult to imagine that an SHG spokesperson becomes the inviting moderator of the next video conference, i.e., the next online self-help group meeting. How many of the existing self-help groups have switched to this possibility, how intensively they are used, how this form of communication is experienced and evaluated by the participants, what consequences this has on fluctuation in the self-help groups is – in numbers – not known. At least, over the last two decades, i.e., before the pandemic, quite a number of experiences with digital peer support has been gathered, shared and jointly analysed.[9–11] In summary, the results show positive effects, such as an improvement in self-esteem, improved self-management or an increase in disease-specific knowledge, but also that online SHGs or peer support are not seen as an equivalent substitute for face-to-face groups or face-to-face peer support. However, as mentioned above, we could not find studies that directly address the impact of the pandemic on SHGs' and SHOs' needs, changes and challenges. Although there are some recent studies dealing with online mutual aid in the pandemic,[12–21] these give either no or only few answers to how SHGs and SHOs deal with these challenges, or whether and how

they are changing. Nevertheless, we expect that there will be some more of these studies in the near future.

Concerning the pandemic's impact on SHGs and SHOs, the authors have participated in many conferences, workshops and meetings on the topic of digitization in self-help over the past two years. SHO representatives, SHG spokespersons and members of the self-help clearing houses have intensively dealt with the challenges the pandemic has confronted them with. During the long period when face-to-face meetings were forbidden, SHGs learnt the need for alternatives. SHG leaders desperately tried to keep in touch with their group members by phone and even by post. Others immediately switched to online meetings with Zoom, Webex or similar. Both SHO and self-help clearing house members offered training and counselling on the use of online communication tools. However, due to the contact ban, the participants often went round in circles. How can you train people to use digital tools if you can only communicate with them using the same digital tools they have yet to learn? Here, most supporters took a step-by-step approach, e.g., by sending printed instructions by post, providing manuals and videos on websites, providing telephone support, etc.

In the self-help landscape, the pandemic produced winners and losers.[12] The losers were mainly those who did not have the necessary IT equipment or the skills to use a PC or smartphone, or both. Several SHGs disbanded quietly; not surprisingly, these were mostly SHGs with older leaders and members. Other losers were those living in regions without sufficient broadband capacity, which is unfortunately a common problem in rural areas of Germany. Not to mention those who simply do not like communicating in front of a screen, or those who have serious concerns about data security and privacy. The winners, on the other hand, were those SHGs that offered and advertized online group meetings, which were attended by many people who would never have visited a local SHG before. Further, people with functional limitations or disabilities that do not allow them to attend an SHG or those who have to travel long distances benefit from these new services.

With these transitions, an important question remains: Are online groups as effective as face-to-face groups? The few studies on this give positive answers. In principle, mutual aid and peer support also work online,[13] especially during the pandemic.[14–18] Ultimately, however, it depends on the people, which form of mutual support they prefer.[19, 20]

With regard to the future, the most frequent conclusion of the self-help representatives is that there will be both forms of SHGs and communication: face-to-face and online, but also mixed forms or in alternating sequence.[21] Finally, almost all of them state uni sono that online meetings cannot fully replace face-to-face meetings in an SHG, because most people want to meet holistically on all sensory levels.

## Conclusions

The causes of the "digital inefficiency" that can sometimes be identified can be focussed on two points: on the one hand, the average age in the executive committees of many SHOs and their adherence to old structures prevents digital developments from being taken up more quickly and/or young members, who are more open to the topic, find it difficult to establish themselves in self-help associations. On the other hand, digitization increases the financial, personnel and time expenditure of an organization, which places clear limits on voluntary work with its focus on the personal exchange of experiences of those directly or indirectly affected. These uncertainties caused by the increase in complexity are particularly evident in the high requirements for data protection and protection against cybercrime.

What conclusions can derive from the survey results for recommendations for action? On a very general level, the following conclusions can be drawn about digitization in mutual self-help:

1. In order to strengthen the SHOs' competencies for digitization, further targeted and advanced training offers are required.[22, 23] These are to be provided within the framework of the self-help funding according to Germany's SGB V § 20 h. Just as important is the bundling of existing services and their provision to interested SHOs (and SHGs), e.g., in the form of a joint platform. An overview of existing tools and their quality assessment could be a first building block for this.
2. Large, long-established SHOs often serve as models for the (non-) digitization of other organizations. At the same time, they are overwhelmed or only partially willing to provide the necessary resources for the digital change due to their history and the diverse tasks. Here, it is important to sensitize and train the managers of the established SHOs for the need for digital change and, if necessary, to provide them with professional support.[24]
3. Young SHOs and their members are often more technology-savvy, more willing to make decisions and – despite a poorer IT infrastructure – use digital media/tools more intensively. A regular exchange with such or similar organizations from the non-profit sector could help to overcome barriers of digitization through mutual learning. Mobilizing new, young members for self-help could also have this effect, but is likely to be difficult to achieve in the short term.
4. Digitization does not only mean technical change, but requires awareness of the risks and costs of this

development. Not everything that is feasible and available on the market is suitable for effective digitization in the area of health self-help. In order to increase the effectiveness of one's own work, examples of good practice should be bundled and communicated. The provision of digital services means assuming responsibility. For this reason, SHO representatives require a high level of digital health literacy in order to classify relevant corresponding opportunities, limits and risks.

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