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SMART HOME

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Guide to needs, problems, interests and solutions in the own home for people with Renal Disease - Bonus: Extended Version -

Project number: 2021-1-DE02-KA220-VET-000033058

Partners



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1. Introduction

This 'Guide to the needs, problems, interests and solutions in the own home for people with Renal Disease' was developed as part of the SWEET HOME project. SWEET HOME is an ERASMUS+ funded project carried out by 6 organisations from 5 different countries (Germany, Spain, Italy, Greece and Belgium). The project runs from February 2022 until August 2024.

The aim of the project is to enable people with different types of disabilities to live a more comfortable, independent and self-determined life in their own homes. This is to be achieved through the use of smart technologies. The ultimate objective is to find suitable and affordable technological solutions for people with different kinds of disabilities and develop free online learning courses for people with disabilities themselves, their support people and professionals who work with them. These learning courses should educate the aforementioned target groups on the different types of smart home technologies available, and how to program and use them.

In order to achieve this goal, Sweet Home carried out a study to get insight in the needs, interests, challenges and solutions in the own home for people with disabilities. This report summarises the results of this study for people with Renal disease, which is one of the focus groups of the SWEET HOME project, alongside people with Down syndrome, visual impairment, hearing impairment, muscular dystrophy, cystic fibrosis and Alzheimer's disease.

What is Renal Disease?

Renal disease (or kidney disease) is damage to or disease of a kidney. It's a common condition often associated with getting older. Kidney disease usually causes a loss of kidney function to some degree and can result in kidney failure, the complete loss of kidney function. Many people with Renal disease are able to live long lives with the condition. Chronic kidney disease is usually caused by other conditions that put a strain on the kidneys.

Regarding treatment plans, individuals can get blood or urine tests to assess the health and function of the kidneys. For severe kidney disease, dialysis and kidney transplants are the most popular options. Dialysis is a treatment where it acts as an artificial kidney and removes

waste products and fluid from an individual's blood. This is accomplished via a machine. Kidney transplants are the surgical procedure of transporting a healthy kidney from a donor into an individual with kidney disease. Both of these options have their pros and con, the success varies by individual.

There are usually no symptoms of kidney disease in the early stages. It may only be diagnosed if you have a blood or urine test for another reason and the results show a possible problem with your kidneys.

Sources: [NHS](#), [Wikipedia](#)

Outline of the report

Chapter 2 of this report will outline what methodology has been used to carry out the analysis, including a description of the interviewees, carried out home observations and participants in the expert roundtable.

Chapter 3 summarises the findings, following the structure of 10 different topics (healthcare and monitoring, personal care, home comfort, home security, entertainment, cleaning, home mobility, energy saving, social participation and e-learning). For each of the topics, interests, needs and challenges will be discussed on the one hand, and solutions and recommendations on the other hand.

Finally, Chapter 4 includes further recommendations for the industry and policy makers.

Disclaimer

The European Commission's support for the production of this publication does not constitute an endorsement of the contents, which reflect the views only of the authors, and the Commission cannot be held responsible for any use which may be made of the information contained therein.

2. Methodology

This study is based on 13 completed questionnaires, 13 interviews, 4 home observations and an expert roundtable with 8 participants. It was completed by some desk research.

Due to the low number of questionnaires, interviews and home observations, this report is not meant to give an encompassing and representative overview of the needs and challenges of people with Renal disease, but is meant to point out some insights and examples.

Questionnaires and Interviews

The respondents taking part in the questionnaires and interviews were five people with Renal disease, five family members of people with Renal disease, and three professionals working with them. The questionnaires and interviews contained questions to identify challenges, interests and opportunities, based on self-assessment for the people with Renal Disease and external assessment for family members and professionals. They also contained questions about the person’s IT skills and familiarity and interest in smart home solutions.

The respondents came from Germany, Spain, Italy, Greece and Belgium. Most respondents indicated they, or their family member or person they support, live in a smaller town (46.2%) or a big city (46.2%), whereas the rest indicated they live in a village (7,7%). Most respondents indicated that they live in a house (53.8%), whereas others indicated they live in an apartment/flat (46.2%).

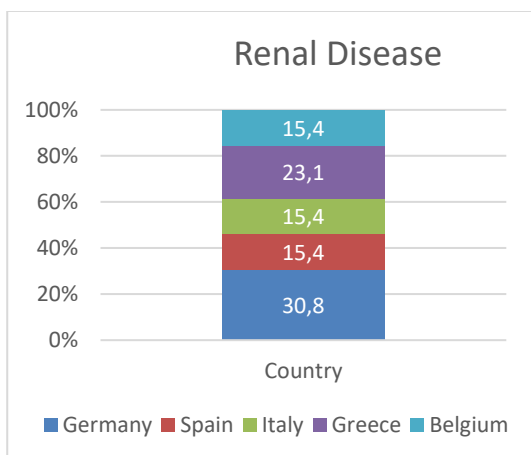


Figure 1: In which country does the survey take place

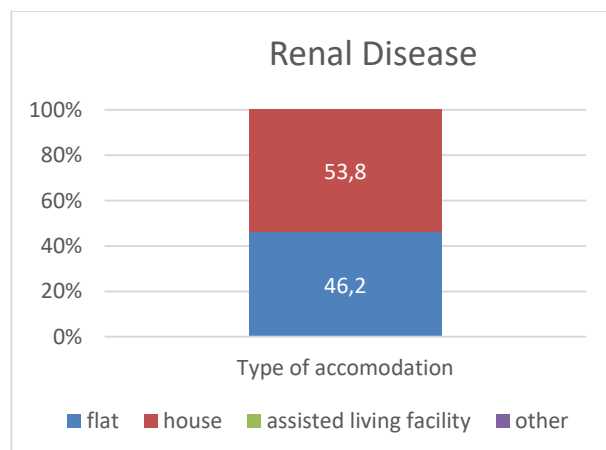


Figure 2: Where do you/does the person you care for live?

Home Observations

Four home observations were conducted in Belgium (1), Germany (1), Greece (1), and Spain (1). The observations were carried out in the place where the person with a disability lives

(whether it is an institution, a family or their own home), observing the people who also participated in the interview and analysing their previous answers. The observer could choose one out of three methods to carry out the observation: 1) by following the structure of everyday routines (observing the person throughout the day); 2) according to the spatial and functional layout of the living space (while making a tour through the house the person shows how they live their daily life); 3) by going over the ten topics of the project. Following the home observation, the observer filled out a log sheet summarising the challenges and needs, the solutions already in place, and how unmet needs could be addressed by technological solutions.

Expert Roundtable

During the online Expert Roundtable, the preliminary findings of the study were shared with 7 experts, who could give their expert view on the needs, interests, challenges and solutions when it comes to the use of smart solutions in the home for people with Renal disease. The experts included two experts in domotics, two nephrologists (one of them was family member of the person with renal disease), an occupational therapist from an association of people with disabilities, and a person with suffering from Renal Disease.

3. Findings

The main challenge for people with Renal disease revolves around feeling comfortable, safe and remaining independent at home. They may find it difficult to manage all the daily restrictions such as the right amount of water intake or salt intake, the blood sugar levels or blood pressure monitoring. In addition, another challenge is to remember to take all the needed pills, especially when memory problems occur that require another person to remind the patient to take pills. If these risks can be mitigated or monitored, they may not need constant supervision and be more independent.

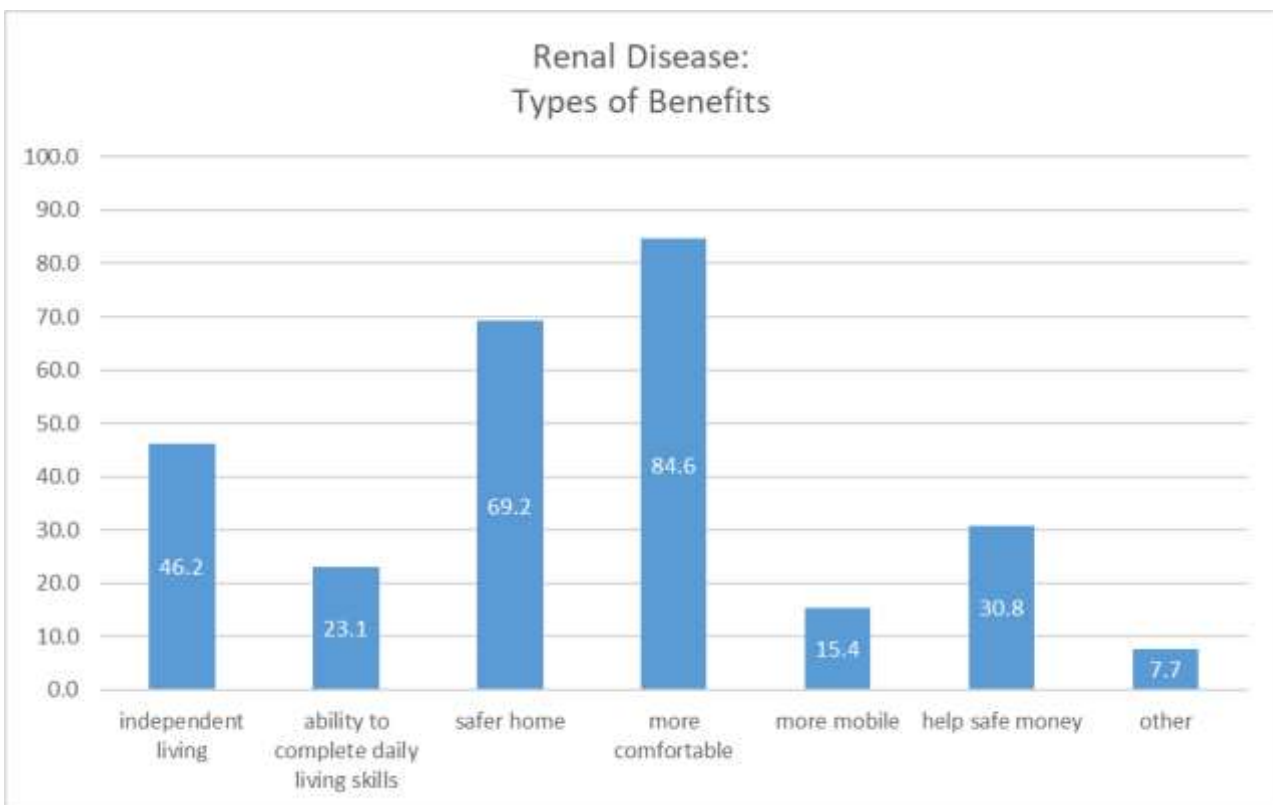


Figure 3: What benefits do you expect can be achieved by the person you support from smart home technologies

There are several smart solutions available that can help people with Renal Disease to live safer and more independently. Important areas where smart solutions can help people with Renal disease social participation (simplified phones and tablets), entertainment (simplified tablets for games, music, watching movies, and Amazon Echo), healthcare and monitoring (automatic medicine dispensers, emergency buttons and health monitoring devices connected to the smartphone), home mobility (beacon and tracker systems), and home comfort (motion sensors for automatic lighting).

The 40% of people with Renal Disease characterize themselves as advanced. The 60% of family member have sufficient level of IT skills, since they declare that they are advanced and experts. 65% of professionals rate themselves as advanced on IT sector.

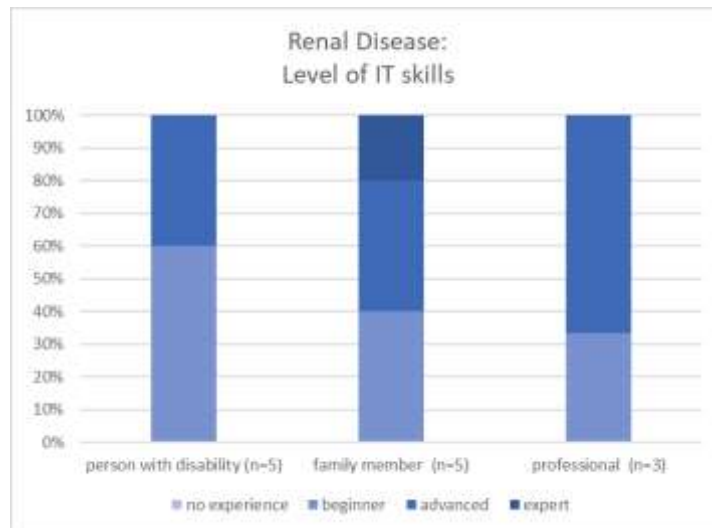


Figure 4: How would you rate your level of IT skills (internet, computer, smartphone)?

3.1 Healthcare and Monitoring Interests, needs and challenges

The completed questionnaires and interviews show that healthcare and monitoring is an important topic for this target group. Due to kidney disease, the patient's water intake is limited. Sometimes he needs to drink a little more, sometimes a little less, which is difficult to manage for him in daily life. In some cases, they are also at higher risk of falling. These topics also came up in the interviews: Several interviewees (mainly family members) expressed interest in a fall alarm and/or emergency button. Two respondents indicated that they/their family member would find it useful to have an easy-to-use phone to be able to call in case of an emergency.

More than 80% of people with disability, family members and professionals show that smart health monitors are useful and most useful.

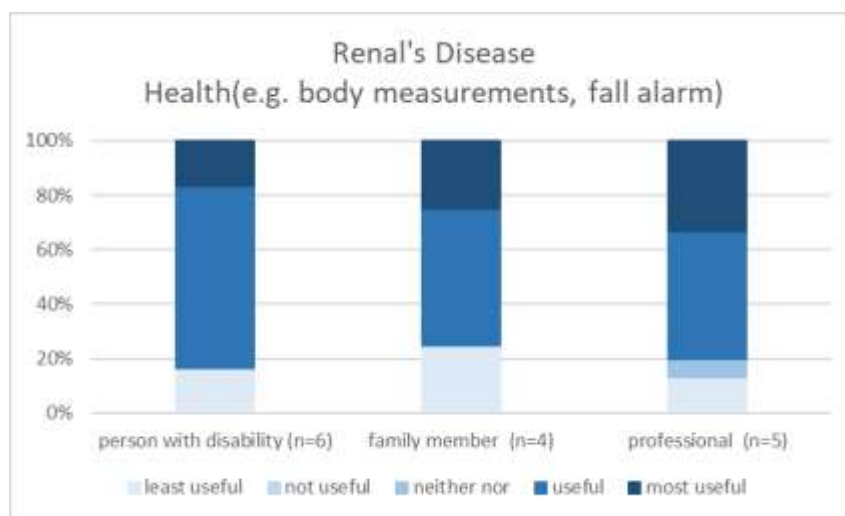


Figure 5: Health

Solutions and Recommendations

- During the expert roundtable, experts agreed that automatic medicine notification can be helpful for those who need to take medication. There are smartwatches and various applications that remind the patients to take medication.
- Due to the disease, blood pressure problems (fluctuating blood pressure) and associated dizziness are common. There is an increased risk of falls. A solution that was suggested by experts for when the person falls is an emergency button which can be used to easily call for help: You can press the button and the caregiver receives a notification. In order for this to work, you need to make sure that the person always has the emergency button with them. Some of these buttons also have a sensor which gives off a location signal (see also section 3.7 on home mobility). Another option is to integrate a fall alarm in a smart watch.
- It would be ideal if all the data needed, such as the drinking quantity, could be stored in an app and if doctors had access to it. This would solve the transportation problem, as the patient would no longer have to be transported to the medical control appointments.

3.2 Personal Care

Interests, needs and challenges

In some cases people with Renal Disease can have difficulties completing daily tasks, which can also be daily tasks related to personal care. It seems that problems with personal care management it is not a main challenge. Only the 20% of the people with disability find it difficult to properly clean themselves in their own home. The same percentage of family members agreed with this opinion.

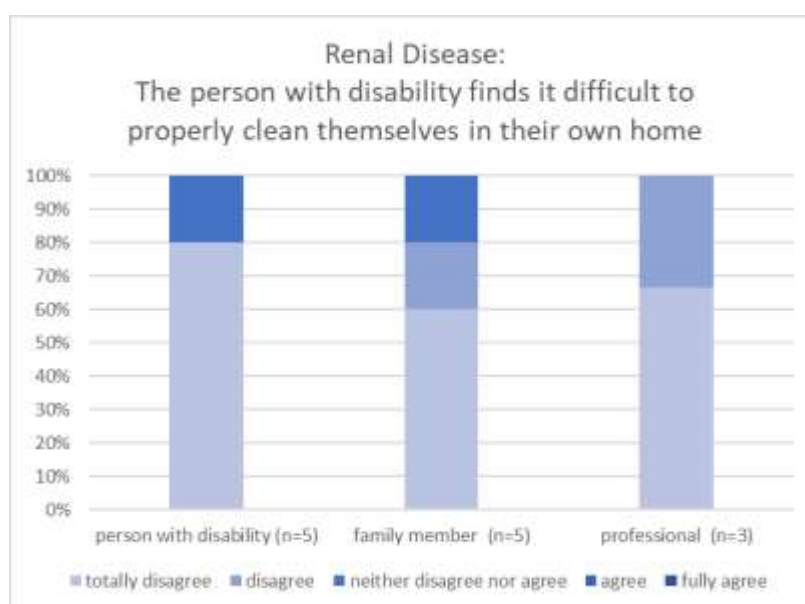


Figure 6: The person finds it difficult to properly clean himself or herself

Solutions and Recommendations

Even though people with Renal disease are generally able to take care of their own hygiene, cleanliness is still very important for them in order to avoid infections to any exposed exit sights (e.g. dialysis catheter/line). That is especially true for the bathroom and the toilet seat.

Utilization of a smart mop robot and even a smart vacuum cleaner could be beneficial for them, to always maintain a good level of cleanliness.

Additionally, there are smart trash cans that can be operated without the need to touch them, guarantying at the same time that the lid will be closed after each usage.

Furthermore, a smart toilet seat could further enhance the hygiene in the bathroom as well as reduce the possibility of infection. Smart toilet seats can be remote controlled and just use water for hygienic cleaning and no direct contact is required.

3.3 Home Comfort

Interests, needs and challenges

When we look at the results of the survey, we see that home comfort can be important for this target group. The 20% of people with Renal Disease found devices for automation/comfort (Alexa, light control, opening/closing of doors) useful and very useful. The same percentage of family member agreed on this opinion. The 60% of professionals, also, responded that automation/comfort devices are very useful.

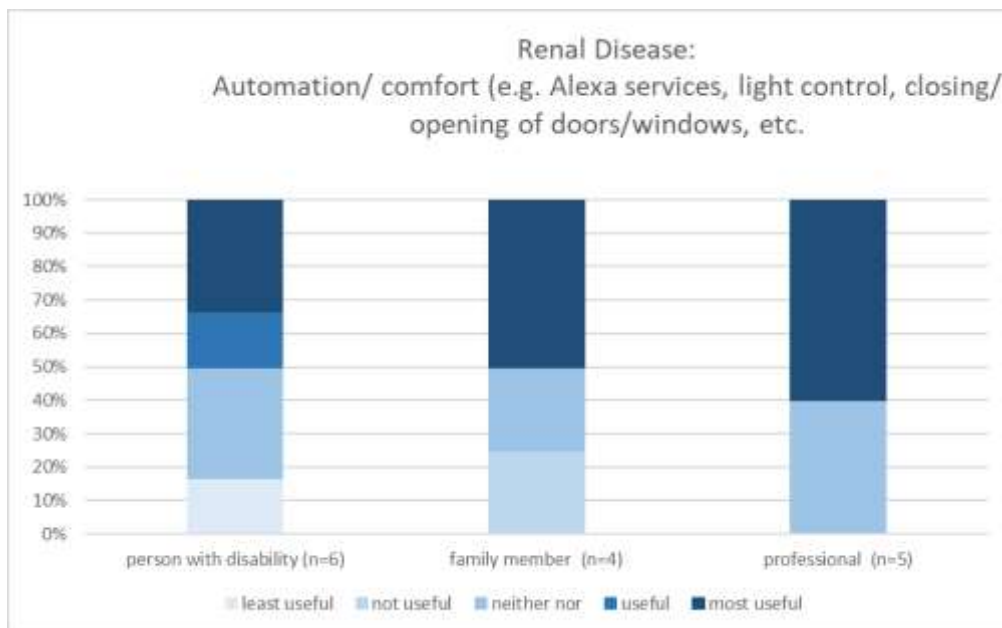


Figure 7: Most useful devices – Automation/comfort (e.g. Alexa services, light control, closing/opening of windows, etc)

During interviews, home observations and experts round table several issues related to home comfort were mentioned because of the great support that home automations can provide in accessibility and autonomy.

Solutions and Recommendations

When social life is restricted, comfort at home is especially important. The family has several TVs in the patient's home to increase his comfort.

Devices like Alexa and Google assistant offer ways to automate chores at home while providing access to means of entertainment (like playing music or narrating an audio book). Moreover, one can make calls and get news updated just with a voice command. Also, with the latest advancements to artificial intelligence (e.g. ChatGPT) a smart assistant could even offer companionship.

3.4 Home Security

Interests, needs and challenges

The 100% of respondents found devices for home security (e.g. camera monitoring and alarm) useful and very useful since the safe home is one of the main challenges. The topic of home security also came up a few times in the interviews.

One participant said that he is afraid about her security (thieves) if she forgets to turn on the alarm.

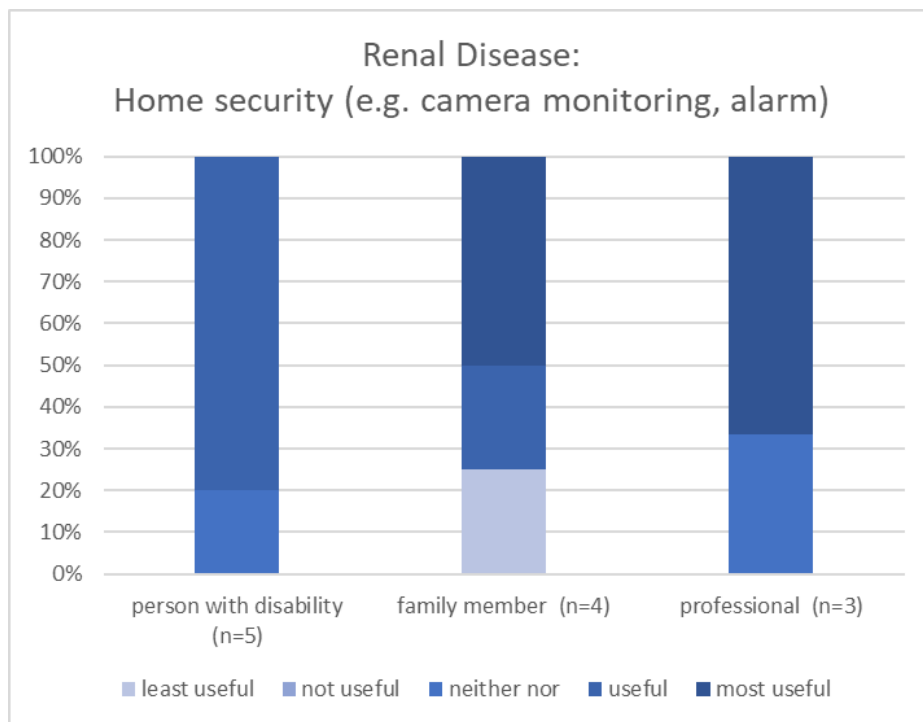


Figure 8: Home security such as camera monitoring, alarm

Solutions and Recommendations

Although this is an important topic for people with Renal Disease, it is questionable if smart solutions in this area are really suitable for them. Most smart security systems work in a way that the user can control the system remotely from a smart phone.

Solutions for home security are mostly IP cameras indoor or/and outdoor. With IP cameras people can monitor home from smartphone with notifications about movement when people leave home. Some cameras have also bidirectional communications. However, if there is a risk of forgetting to activate the alarm when the person leaves the house, potentially the alarm can be connected to the GPS signal of a smartphone, so that it gets automatically activated when the person leaves the house and gets deactivated again when the person approaches.

Safety is a large concern for families and a fall/panic button was highlighted very often.

The new market of smart alarms is based on cloud storage and security alarm centres. Different sensors can detect any potential emergency or intrusion before it takes place. If an intrusion or emergency occurs, security experts respond in seconds to help people manage the event.

3.5 Entertainment

Interests, needs and challenges

Entertainment at home is important for people with Renal Disease, as the home is where they usually spend a lot of time. As you can see, 80% of people with disability agree or fully agree that they have access to various entertainment activities at home. All the family members of patient's agreed that the patients have access to entertainment activities

80% of patients and the same percentage of family members found entertainment/ communication devices (e.g. smartphone, smart tv) useful or very useful. 70% of professionals think the same.

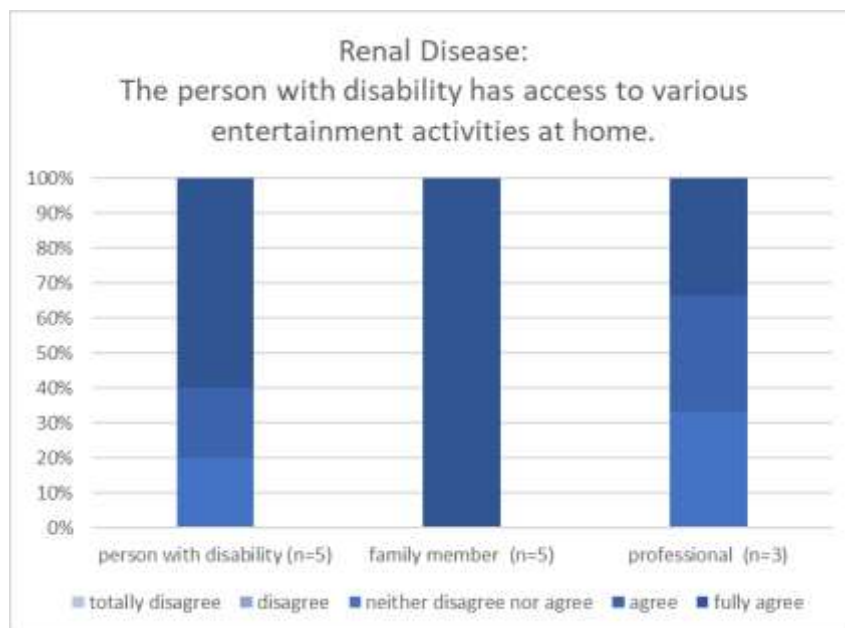


Figure 9: The person has access to various entertainment activities at home

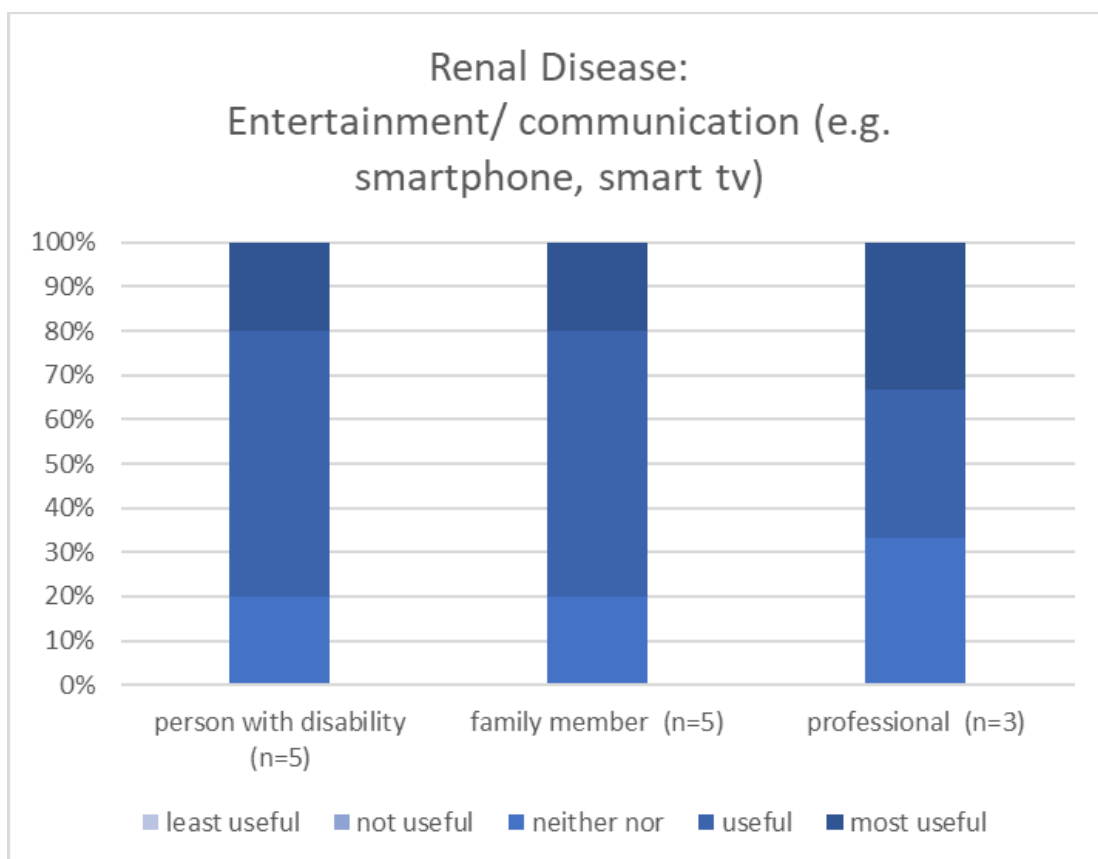


Figure 10: Most Useful Devices – Entertainment/Communication activities (e.g. smartphone, smart tv)

Solutions and Recommendations

- The professionals agreed that simplified tablets can offer solutions, as it allows people with Renal Disease to play games, listen to music, and watch series or movies. The interface is more intuitive.
- In some cases, systems which are voice-controlled are easier for people with Renal disease to use. For example, Amazon Echo can be used to play music or listen to audiobooks. The Smart TV can also be connected to a smart home system such as Alexa. This might make it easier for some people to navigate the menu.
- Next to the more obvious means of entertainment, it can also help people with Renal Disease if they can continue to exercise daily tasks like doing the laundry or grocery shopping. It can make them feel less bored, more independent and thereby it can be good for their self-esteem. The next section (3.6) elaborates on this topic.

3.6 Cleaning, cooking and household activities

Interests, needs and challenges

One of the main challenges for people with Renal Disease is to remain independent at home, and the ability to perform basic daily tasks such as cleaning, cooking and household activities. This is shown by the survey and came forward in the interviews and expert roundtable as well. Although the 40% of people with disability agreed that "Cleaning the home is a challenge for the person, the 60% of family member agreed or fully agreed that cleaning home is a challenge.

One interviewee explained that very high cleaning standards must be maintained in the bathroom

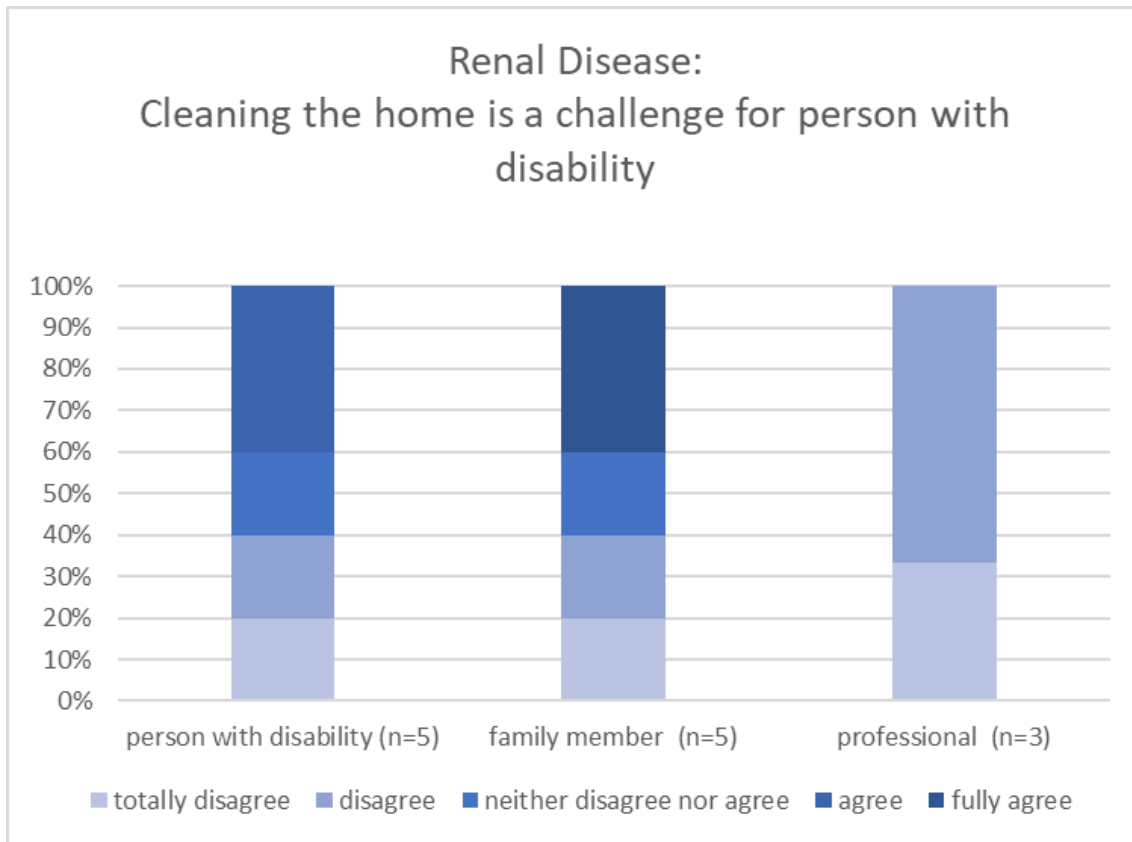


Figure 11: Cleaning the home is a challenge for the person

Solutions and Recommendations

Big autonomy limitations require some help from someone in cleaning home, but smart vacuum cleaner is a very useful and widespread device. Other smart home appliances like smart washing machine or smart dishwasher can help but only giving autonomy in starting operations at a certain time for example.

3.7 Home mobility

Interests, needs and challenges

Most of the participants taking part in the survey and interviews indicated that the person with Renal disease is still mobile. To the question “The person with disability has difficulties in moving around their home” only 40% of people with disability agreed or fully agreed. Nevertheless 60% of family member and 65% of professionals agreed that home mobility devices such as elevators, chair lifts will be very useful.

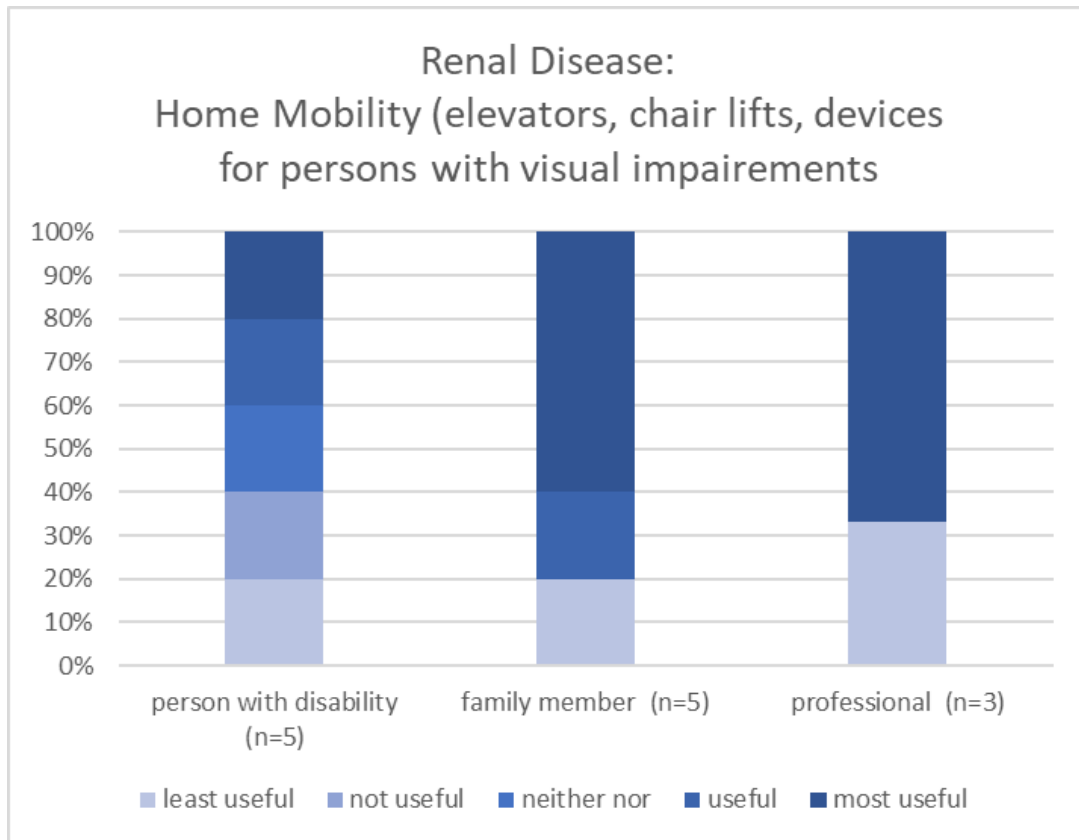


Figure 12: Home mobility solutions

Solutions and Recommendations

- In specific cases, when a person with Renal Disease is less mobile because of their physical state, (smart) mobility devices can potentially help, as long as they are easy to use (this should be assessed on a case by case basis).
- To increase mobility around the house a beacon and tracker system can be useful. Some of these systems allow the caregiver also to see at all times where the person is.

3.8 Energy saving

Interests, needs and challenges

Based on the questionnaire, energy saving is an important topic for people with Renal Disease.

Most people with disability respondent to questionnaire (60% agree and fully agree) think that his/her home is energy efficient. The 60% of family members agree and fully agree with the same statement, while 65% among professionals agree or fully agree.

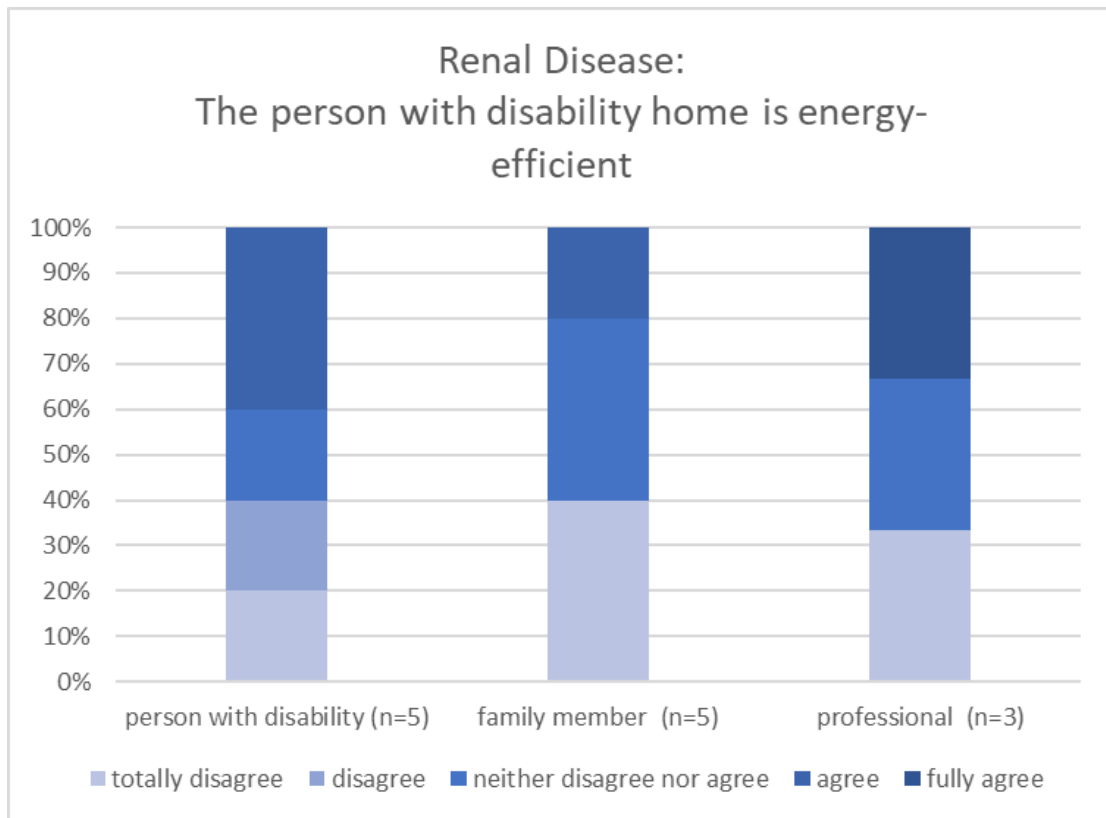


Figure 13: The person with disability home is energy-efficient

Solutions and Recommendations

Due to disease the house must not be too cold, it must always have a certain, stable temperature, especially the bedroom. In addition, hot water is always needed. Many smart systems can help in energy saving. During interviews, observation, and roundtable these devices were named: smart thermostat, smart illumination systems, smart socket that they allow the users to control any connected device (traditional ones above all) and show energy consumption. In home automation systems collaborative logics can help in reduce energy consumption: for example, the thermostat can stop heating systems if windows are open. The lights can be turned off automatically if nobody is in the room or if there is enough light and a display can show energy average or instant consumption to help inhabitants to have more energy-intensive lifestyles.

3.9 Social Participation

Interests, needs and challenges

On the topic of social participation all of the people with Renal Disease agreed or fully agreed that they feel well-connected to the community in which they live in. The 80% of family members fully agreed with this statement, while 65% of professionals agreed or fully agreed.

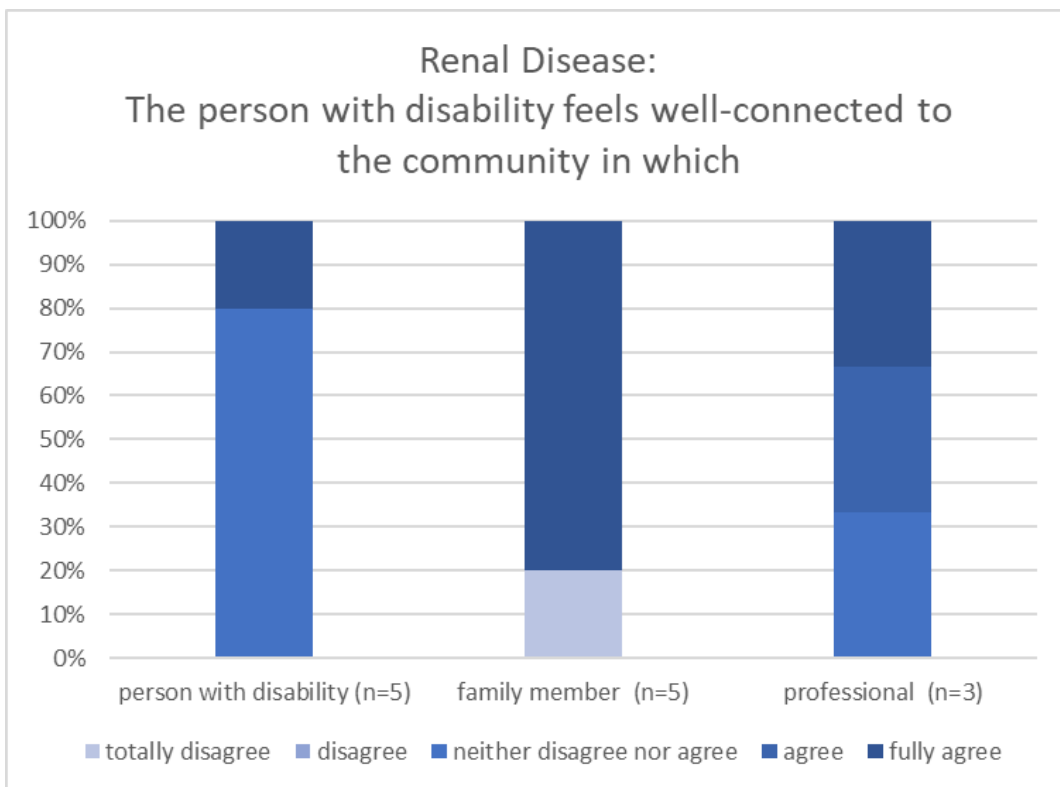


Figure 14: : The person with disability feels well-connected to the community in which they live in

Solutions and Recommendations

Social system and help from professional and informal caregivers can help in people with Renal disease social participation but, especially ,at advances stages of illness, social networks applications and accessibility to tablet, smartphone or PC can give a great support both in face to face and remote communication and consequentially help in social participation.

The most important recommendation is to provide support to find the right communication channel with an assistive technology multidisciplinary team. In this way accessibility problems to device like smartphone, tablet or Personal computers can be overcome with software and/or hardware adjustment.

3.10 E-learning

Interests, needs and challenges

About the e-learning, most of the questioners responded that they prefer video and online courses, while following face-to-face and textbook methods.

One patient in roundtable refers that he prefers face-to-face to e-learning or reading a document. Also, videos are a good way, as long as it is available in the local language.

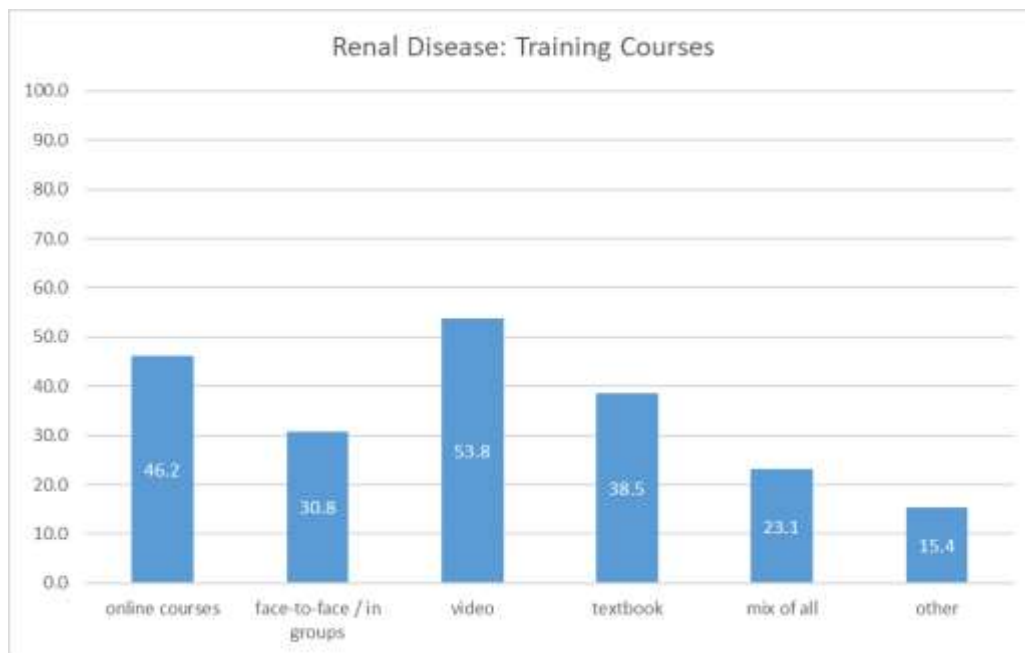


Figure 15: Training courses

4. Recommendations for the industry

- People with Renal Disease should be involved in developing and testing of products.
- It is important not to make assumptions on the needs of individuals – we should not generalise as needs and preferences can be very different from person to person.

- Costs of smart homes and home automation are a central issue. Economic contribution from national or regional agencies should be improved to foster people's autonomy at home and consequently reduce cost for assistance.
- Standardisation of smart devices so that everything can work together, regardless of the brand. This way training people to use smart devices would be easier and would apply to all the smart devices.
- Easier and more accessible training material for smart devices, taking into account older and technologically illiterate people.



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