

DIGITAL HEALTH: INCREASING THE IMPACT WITH PERSONALIZED DESIGN

WHITEPAPER

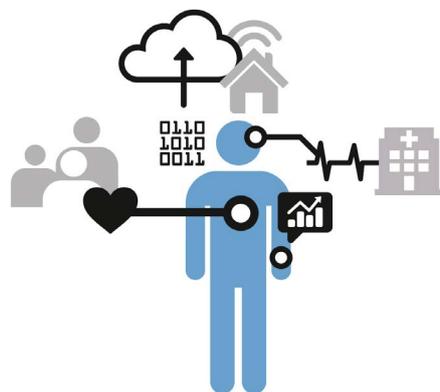
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TNO innovation
for life

› Pepijn van Empelen
Wilma Otten
Hanneke Molema
Jolanda Keijsers
Ronald Mooij

Digital health is considered the 'holy grail' of effective and sustainable health(care). It uses the latest technology, apps and data to support and improve health. Digital health tools can benefit both patients and healthy individuals, with support and advice. But healthcare professionals, policymakers and scientist can also benefit from the (big) data and insights collected by digital health applications.

A well-known example of digital health is eHealth, which provides information- and communication technology, mostly online.¹ There are also advances being made with sensors and wearables and robotics.

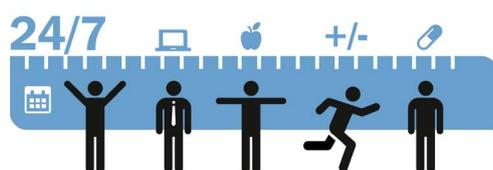


Current impact of digital health does not extract all value deemed possible. This requires far more work and insight in technical as well as practical innovations. Entrepreneurs, scientists, policymakers, professionals and individuals need to work together to address the challenges. The main challenge is to develop digital health services and products that provide effective support, and help people to manage their health in the face of physical, social, mental and social challenges.²

CURRENT STATUS AND ADVANTAGES OF DIGITAL HEALTH

Digital health is mainly developed in two sectors. In the traditional medical sector, innovations that offer personalized clinical decision-making, tele-monitoring and support at home are increasingly used. In the lifestyle and wellness sector, we see IT, food, wellness and fitness companies developing novel eHealth solutions and applying them in services and products. Think here of self-management and lifestyle support for diet, physical activity, sleep and stress.

Most stakeholders acknowledge that digital health can improve diagnosis and provide insight into personalized risk factors.³ Also, it can improve the quality of informed decision-making and support. Moreover, digital health can help patients and healthy individuals to better understand health and disease. It can motivate and support lifestyle changes or disease management by reminding people of their goals, appointments or medication, and help people monitor progress. Since digital health is accessible 24/7 and can be used anonymously for embarrassing behaviors, like addictions, it reaches people that are generally difficult to reach.⁴



These advantages of digital health have been shown in various evaluation studies. But there is considerable variation in effectiveness. It is not always clear why some online interventions are effective and others not.⁵ Moreover, reach and attrition of users is a serious problem, because a significant number of people drop out when using internet-based interventions.⁶

FOCUS OF TNO

At TNO, we have identified four areas that are of crucial importance to increase the impact of digital health:

- **Personalized design of digital health** will enhance and retain use and sustain behavior that promotes health;
- **Valid and reliable predictive models for health and diseases** will integrate personal data, large health data bases and domain knowledge for a complete overview;
- **Advanced data profiling** through new and existing (big) data science techniques will make the technologies more robust;
- **Data privacy and security** will protect users while maintaining interoperability and standardization.

In this paper, we focus on the first area: personalized design of digital health. We demonstrate how we can use design to improve effectiveness and use of personalized digital health interventions. 'Effective' means that it contributes to behavior promoting health and wellbeing. From research, we know more personalized interventions, are more effective.^{7,8} 'Personalization' is a broad term that reflects to a variety of techniques in digital health design, including the use of personal data to customize information, feedback and support (i.e., tailoring⁹).

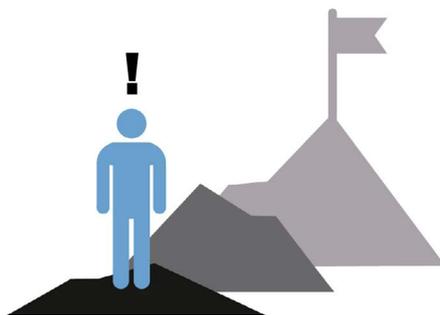
DESIGNING MORE EFFECTIVE PERSONALIZED DIGITAL HEALTH

We believe that digital health's limited success is mainly due to design. We see many digital health interventions that are rather static and textual. They cannot adapt information and support over time, as their users evolve. In the same line, digital health often does not adapt to different populations, like people with low (e)health literacy, a low educational level, or those from particular cultural backgrounds. Further, eHealth tools are often stand-alone applications, which cannot make effective use of big data. Moreover, many do not use the state-of-the-art knowledge on behavioral change strategies.

Our view is that most digital interventions or applications are not personalized (enough). TNO develops techniques and knowledge to improve personalized design. If we take into account the following four different aspects of design, these applications will be more effective and better used.

1. INCLUDE EFFECTIVE (SUSTAINING) BEHAVIORAL CHANGE STRATEGIES

Effective intervention strategies have shown to change behavior sustainably, including dietary habits, smoking, alcohol use and physical activity. In the past ten years, considerable work has been devoted to understanding which behavioral change strategies contribute to effective lifestyle and disease management interventions. These strategies include self-monitoring, prompts that identify barriers to change behavior and how to overcome these barriers, techniques that prevent users from falling back into the former unhealthy behavior ('relapse' prevention), and the provision of performance feedback.^{5,10,11,12,13}



Despite the existing evidence, we see that current apps and online interventions that target smoking cessation, weight loss, diabetes, exercise, alcohol consumption, dietary consumption, and employee health hardly use these behavioral change strategies.^{14,15} And if applications do use behavioral change strategies, the focus has mainly been on starting the behavioral change and less on sustaining it.

To increase digital health effectiveness, we must integrate theoretical models and behavioral change strategies into Information and Communication Technology (ICT) state-of-the-art.^{16,17} For example, by applying the theories promoting behavioral change that is sustainable in the long term.¹⁸ One motive for sustainable change is that not much effort is needed to execute the behavior. People want cues that unconsciously drive behavior. Such 'nudging' can be as simple as a WhatsApp message that shows a picture of fruit at 4 PM, to prevent the user from eating cookies during an afternoon snack moment.¹⁹

TNO EXAMPLE

The Engagement Game is a systematically designed, serious game. It aims to raise managers' awareness and self-confidence to stimulate employees' engagement and reduce work-related stress. By playing the game, managers have an effective way to start dealing with these issues. It was developed together with experts on stress and engagement, serious game developers, and experienced managers.

The Engagement Game is based on the Jobs Demands Control model.²⁰ This model describes factors that influence the balance between job demands and resources. Effective balance causes engagement, and ineffective balance causes stress. We developed scenarios and rules to translate the model into a game.

In the game, the player has to manage six employees with their own job demands, resources, competences and ambitions. During the game, all kinds of events take place. The player must react by choosing interventions for the employees. The interventions change employees' job demands and resources which affects their stress or engagement.

Managers play the game to explore which interventions have positive or negative effects on employee stress and engagement. The results show that managers enjoy the game, that they can translate the game to their actual work situation, and that they learn how their actions influence their employees' levels of stress and engagement.²¹

2. INCLUDE INTERACTION STRATEGIES FOR PREVENTING DROP-OUT

Digital health can only be effective when it is actually used. Our research shows that usability and engagement not only increase the fidelity and continuity of use, but also contribute to the effectiveness of an intervention.⁵ Therefore, maximizing user involvement and retention should be taken into account in the design of digital health for healthy individuals/patients as well as healthcare professionals.



To prevent dropout, we include interaction strategies in the design of applications. One example involves creating a therapeutic-client working relationship between the user and the digital health intervention.²² Different delivery modes, such as a chat avatar (see this [Dutch example](#)) or social robots can be used as 'virtual agents' that provide support.^{13,23} Further, we see integration with gamification principles, like competition, incremental steps in mastering the game, and rewards.^{24,25} Cultural tailoring is another example of how to improve (technology) acceptance, loyalty and effectiveness of digital health.²⁶ This can be tailoring to gender, age, religion, ethnic background or health literacy.

TNO EXAMPLE

PAL is short for 'Personal Assistant for healthy Lifestyle'. It was developed for children with Type 1 Diabetes Mellitus. These children face high demands for self-management to prevent health problems in the short term (and long term). For children, self-management requires motivation and perseverance. It also requires a partnership with their parents and professionals. These caregivers play an important role. However, diabetic children need to become more self-reliant at an early age, in order to ensure good self-management in adolescence.

The PAL system focuses on a personal robot 'buddy' for children, including an avatar and app. There is also an authoring tool for healthcare professionals and an information system for parents (www.pal4u.eu). The robot, named Charlie, is a humanoid, embodied and interactive agent. Children play educational games with Charlie, interact socially and develop a bond. Parents monitor the child's development. Healthcare professionals can direct the PAL system, and set goals for the child to achieve.

Overall, PAL makes diabetes management fun for kids. At the same time, parents can keep an eye on them and professionals can guide the content. For example, they can offer a game about insulin if kids find it difficult to administer it themselves. Through the games, children develop self-confidence and self-management skills (like counting carbs, recognizing symptoms, injecting insulin). Interaction with Charlie increases the child's intrinsic motivation. The long-term benefits include prevention of glucose dysregulation, improvement of well-being and health and reduction of the economic burden on the healthcare system.²⁷

3. MAKING TIMELY AND ADAPTIVE INTERVENTIONS

Delivering timely interventions involves making interventions available at the time they are needed or most likely to be accepted.²⁸ Adaptive interventions allow for and incorporate changes, also changes over time. This is important, because each individual user may use the intervention in different situations and users evolve over time.

Developers need to build 'just-in-time adaptive interventions' that can contribute to optimized compliance, credibility, satisfaction and (cost-) effectiveness.²⁹ However, just-in-time adaptive interventions are still in their infancy stage. They cannot yet predict challenging situations. These are situations in which an individual may experience a setback or lapse to the former unhealthy behavior.^{30,31} It is crucial to understand when a particular individual is most vulnerable. This is the specific time when support is needed most, and when interventions must be most adaptive.



Timely and adaptive interventions require more intelligence in design. This will make a crucial distinction from current mainstream digital health solutions. We need to include machine learning that recognizes patterns, and develop algorithms that predict the likelihood of a challenging situation before it occurs. Wearables and sensors provide opportunities for contextual and instant sensing of risk indicators, which, when linked to appropriate behavior change techniques, could provide the timely support needed in that challenging situation.

TNO EXAMPLE

The European project Power2DM empowers individual adults with type 1 or type 2 diabetes by optimizing self-management. In the project, predictive decision support and timely and adaptive coaching tools are being developed and tested.

Predictive decision support is based on models that predict the course of diabetes type 1 and or 2. These models are based on a patient's data and are further developed and applied in concrete hospital settings. The models are used to support patients themselves as well as patients and professionals together in making shared decisions on self-management goals.

Coaching focuses on goal management. Once self-management goals are set, a personal health tracking system should monitor how a patient progresses on the goals. The system should reward goal progress. However, when a patient deteriorates, timely interventions should help get him/her back on track. Hereto, goal deterioration will trigger an analysis to uncover underlying reasons. Interventions should be adaptive to the underlying reasons. For instance, if the frequency of glucose monitoring is too low because the patient forgets, the system can send reminders. However, if the reason for insufficient monitoring is the patient's fear that others will detect he/she has diabetes, a combination of interventions is offered, such as tips for injecting in privacy, suggestions for how to disclose being a diabetic, self-esteem boosters, and a visit to a healthcare professional.

4. SYSTEMATIC, DESIGN-INTEGRATED SOLUTIONS

Thus far, most digital health applications seem like a black box³⁰, and they are often stand-alone. To open the black box, we need to use existing frameworks on systematic intervention development³² and situated cognitive engineering³³. If these frameworks are used to structure an intervention's design, this can promote effectiveness and facilitate the interventions' transparency and adaptation possibilities.^{11,25,34,35} Moreover, they provide ways to evaluate and understand what works, for whom and when.^{17,36}

Next, it is essential that digital health is more integrated into real life. To achieve this, the expertise and input of different stakeholders needs to be included in the design. Stakeholders are not only ICT experts, data scientists and behavioral change experts, but also individuals (healthy or sick), informal care givers and healthcare professionals. We need to understand their pains and gains, to design interventions that will actually apply to their daily challenges. We need to ensure that the use of interventions will be rewarding. Also, we need to include new directions for gathering data in intervention design. This will help us fully capture and understand the impact of an intervention at person-level and in real life. Hereto, we must design and allow for evaluation alternatives to the traditional Randomized Controlled Trial.



TNO EXAMPLE

'StartingTogether' (SamenStarten in Dutch) is a tablet-based decision support system for youth healthcare nurses and parents. TNO developed this application in close cooperation with these target groups. When nurses have at-home conversations with parents who need help for their child, the app supports these conversations. It displays icons that represent various topics, like child development, education and finances. Parents can choose the topic they want to discuss by clicking on an icon. This encourages parents from a variety of backgrounds to talk about more sensitive topics, like bullying siblings. The app provides information on the chosen topic from diverse sources, like websites, brochures from youth healthcare institutions, and organizations in the neighborhood that offer assistance. The nurse presents this information, and also emails it to the parents, along with a summary of the conversation.

StartingTogether was evaluated and further developed. The evaluation showed positive effects. For instance, parents could better express their questions and worries, and nurses were enabled to better support parents. The next step was an implementation project to identify barriers for implementation and use in daily practice. This project proved that effectiveness depends on, for example, how much the management of a youth healthcare organization supports the app, and how well nurses are trained in using it. Based on this insight, we developed an action plan for implementation of StartingTogether in various Dutch municipalities.³⁷

MAKING IT WORK IN PRACTICE

Personalized digital health empowers users to manage their own health and make autonomous, informed choices. It supports users in self-management. It helps them sustain behavior changes that promote health, especially if users receive timely support in vulnerable situations.

This paper sheds light on the technical developments needed to personalize digital health design. Developments in which TNO has an active role. We support companies who work on products and services for personalized digital health. Our goal is to ensure their products and services are more effective and better used.

But the challenges for personalized digital health do not merely require theoretical and technical developments. We also see several practical challenges that need our careful attention, if we want to successfully implement digital health.

MAKE DIGITAL HEALTH THE EASY CHOICE

We need to make people more aware of the current possibilities of digital health. In 2015, the yearly Dutch eHealth monitor showed that patients are interested in the digital health possibilities.^{38,39} Yet, in 2016, the monitor showed that patients often do not know which services and products are available. TNO sees several possibilities to increase digital health awareness, and make it the easy choice.

Digital health needs to be part of the larger ecosystem in which people live. For instance, in their homes (domotica), in the city (smart cities), in transportation (smart car, bike), or at work. We try to converge these fields. We develop workplaces with employee health programs that integrate digital health technologies. Life events, like retirement, may be used to break traditions and introduce something new, including digital health. Also, (healthcare) professionals could lead by example and demonstrate the possibilities of digital health. [TNO's iGrow app](#), for example, works this way. The iGrow Pro is actively used by professionals in youth healthcare to monitor the growth of babies and young children (height and weight). This way, the professionals familiarize the parents with the app. Also, they discuss how parents can use the information and insights the app provides. In 2014, nearly 100,000 parents used the smartphone app to log their child's height and weight. With the app, parents also receive tips and advice on healthy food, activity and sleep.

MAKE PEOPLE OWNERS OF THEIR OWN DATA

To make digital health work in practice, we also want to address the issue of data ownership. In many applications, people cannot, or only limitedly, own and manage their own data, including the choice to share information. This is not merely a matter of privacy and security. Of course, exchanging personal digital data between patients and providers or other parties is difficult today, both technically and ethically. However, many stakeholders currently create value from individuals' personal health data, although the individuals themselves receive no value from their own data.

To counter this, we see the development of new business models and initiatives. One is Health Data Cooperatives. These cooperatives enable individuals to securely store, manage and control access to their personal, health-related data. Users can view and analyze their personal data, and provide access to sets of that data to others. An example is [MIDATA.coop](#), of which TNO is a partner. MIDATA.coop poses that individuals need to be provided with a platform to safely store, manage and share their own health-related data.⁴⁰ If such a platform is organized as a cooperative, members – and not shareholders – own and control it. The members determine which data they want to share, which revenues they want to generate, and how these are shared. With MIDATA.coop, we are exploring how the platform should be designed technically, ethically and legally.

MAKE DATA MORE AVAILABLE

Next, to increase the potential of digital health, all stakeholders need to share data for research purposes. Making better use of available data is key to attaining improved healthcare and empowerment. To understand health and increase possibilities for health management, relevant data include personal medical data, data on (real-time) behavioral and social factors, and data on the person's environment. Moreover, sharing individuals' data improves the personalization of care. It contributes to better stratification and prognosis. Also, combining (longitudinal) data optimizes causal inferences.

In this respect, TNO supports and is part of **Health RI**, the Dutch Personalized Medicine & Health Research Infrastructure. In Health RI, the partners envision a globally unique research infrastructure in the Netherlands. It will both drive and support cross-disciplinary research into personalized medicine and health, and optimize personalized healthcare. Hereto, the partners will create an infrastructure for a national platform for high-quality experimental design and measurement, data stewardship and data analytics. A prerequisite for, and working mechanism of, a well-functioning infrastructure is active involvement of individuals and their collectives in its development. Therefore, people need to be informed about the value their data can create for science, population health and improving the health of other individuals. And of course, from the perspective of ownership, people then have the right to make personal decisions about which data they collect and share with others, and what they want in return (information, education, science or other revenues).

WILL YOU JOIN US?

TNO is ready to develop more personalized digital health services and products that actually effectively support individuals to manage their health in the face of physical, mental and social challenges. With our knowledge and experience, we can include effective (sustaining) behavioral change strategies, include interaction strategies for preventing drop-out, make timely and adaptive interventions and systematically design integrated solutions for your applications. Moreover, we are closely involved in projects to make digital health work in practice, on a large scale. To make digital health the easy choice, to make people the owners of their own data, and to make data more available for research. The more partners we have, the faster we will achieve our ambitions. Will you join us?

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COMPETITIVE STRENGTH OF INDUSTRY
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