

# Personal responsibility for health: the impact of digitalisation

Andrea Martani\*

*Institute for Biomedical Ethics, University of Basel, Basel, Switzerland*

Georg Starke

*Institute for Biomedical Ethics, University of Basel, Basel, Switzerland*

## Abstract

*Fostering the personal responsibility of patients is often considered a potential remedy for the problem of resource allocation in health care systems. In political and ethical debates, systems of rewards and punishments based on personal responsibility have proved very divisive. However, regardless of the controversies it has sparked, the implementation of personal responsibility in concrete policies has always encountered the problem of practical enforceability, i.e. how causally relevant behaviour can be tracked, allowing policies of this kind to be applied in a fine-grained, economically viable and accurate fashion. In this paper, we show how this hurdle can be seemingly overcome with the advent of digitalisation in health and delineate the potential impact of digitalisation on personal responsibility for health. We discuss how digitalisation – by datafying health and making patients transparent – promises to close the loophole of practical enforceability by allowing to trace health-related lifestyle choices of individuals as well as their exposure to avoidable risk factors. Digitalisation in health care thereby reinforces what Gerald Dworkin has called the causal aspect of personal responsibility and strengthens the implicit syllogism that – since exposure to risk factors happens at the individual level – responsibility for health should be ascribed to the individual. We conclude by addressing the limitations of this approach and suggest that there are other ways in which the potential of digitalisation can help with the allocation of resources in health care.*

## I. Introduction

Should people who contribute to their own poor health be held accountable for it? The question whether enhancing personal responsibility for health is a just policy-choice enjoys a prominent role in the political as

---

\* DOI 10.7590/221354020X15815920230933 2213-5405 2020 Journal of Medical Law and Ethics

well as the scientific debates concerning the allocation of health care resources.<sup>1</sup> The increasing importance that this argument has acquired in recent decades can be related to several factors. First, with the population ageing and the incidence of non-communicable diseases increasing, health care services struggle to keep up with the populations' health needs. Second, with scarcity of resources hitting many health care systems – albeit to different extents – there is an increasing need for socially accepted criteria to allocate the available money. Third, the advancements of medicine raise popular expectations of receiving effective treatment with respect to an increasing number of conditions regardless of their cost – especially when those illnesses are life-threatening and affect children.<sup>2</sup> Fourth, research is showing that for common non-communicable diseases whose treatment significantly contributes to health expenditure – such as cardiovascular diseases, diabetes and even cancer – a few changes in lifestyle would reduce the occurrence of many of these illnesses.<sup>3</sup>

In this context, it is easy to understand the appeal of the idea that people who contribute to their own poor health should be personally and financially responsible for it. In England, for example, some local Clinical Commissioning Groups (the public bodies responsible for the planning and commissioning of health care services in England's National Health Service) have been contemplating plans to restrict free<sup>4</sup> elective surgery for smokers and obese patients.<sup>5</sup> Similarly, individual co-payments for health problems resulting from medically unnecessary cosmetic surgery, tattoo or piercing were increased in Germany,

---

<sup>1</sup> See, for example, M. Minkler, 'Personal Responsibility for Health? A Review of the Arguments and the Evidence at Century's End', *Health Education & Behavior* 26 (1999):121-140; A.M. Buyx, 'Personal responsibility for health as a rationing criterion: why we don't like it and why maybe we should', *Journal of Medical Ethics* 34 (2008):871-874; K. Sharkey & L. Gillam, 'Should patients with self-inflicted illness receive lower priority in access to healthcare resources? Mapping out the debate', *Journal of Medical Ethics* 36 (2010):661-665; A.M. Baker & L.M. Hunt, 'Counterproductive Consequences of a Conservative Ideology: Medicaid Expansion and Personal Responsibility Requirements', *American Journal of Public Health* 106 (2016):1181-1187.

<sup>2</sup> See, with respect to this point, the literature on the "rule of rescue", e.g. Bettina Schöne-Seifert: 'The 'rule of rescue' in medical priority setting: Ethical plausibilities and implausibilities', *Perspectives in Moral Science* (2009):421-430.

<sup>3</sup> See e.g. S. Barquera, A. Pedroza-Tobías, C. Medina, L. Hernández-Barrera, K. Bibbins-Domingo, R. Lozano & A.E. Moran, 'Global overview of the epidemiology of atherosclerotic cardiovascular disease', *Archives of medical research* 46 (2015):328-38.; I. Soerjomataram, E. de Vries, E. Pukkala & J.W. Coebergh, 'Excess of cancers in Europe: A study of eleven major cancers amenable to lifestyle change', *Int. J. Cancer* 120 (2007):1336-1343; I. Soerjomataram, K. Shield, C. Marant-Micallef, J. Vignat, C. Hill, A. Rogel, G. Menvielle, L. Dossus, J.N. Ormsby, J. Rehm & L. Rushton, 'Cancers related to lifestyle and environmental factors in France in 2015', *European Journal of Cancer* 105 (2018):103-113; Y. Zheng, S.H. Ley & F.B. Hu, 'Global aetiology and epidemiology of type 2 diabetes mellitus and its complications', *Nature Reviews Endocrinology* 14 (2018):88.

<sup>4</sup> Free at the point of use.

<sup>5</sup> V. Pillutla, H. Maslen & J. Savulescu, 'Rationing elective surgery for smokers and obese patients: responsibility or prognosis?' *BMC Medical Ethics* 19 (2018), 28.

based on the Competition Reinforcement Law passed in 2007.<sup>6</sup> Even in Switzerland, a country where ‘there is little explicit rationing of services [...] [and] cost is a concern, but there has been no cost explosion’,<sup>7</sup> rising insurance premiums and out-of-pocket spending have reinforced calls to increase personal responsibility for health. In a recent editorial of the *Schweizerische Ärztezeitung*, the author expressed this point strongly:

People without personal responsibility are overweight, smoke and sit in front of their screen instead of doing exercise. They eat too much sugar, too much fat and few vegetables. They ignore the suggestions of the professionals and run to the doctor when they feel ill, without any second thought. And we – the slim, fit and sporty non-smokers – co-pay for that. We – the ones who take personal responsibility seriously – will be punished with ever higher insurance premiums.<sup>8</sup>

The success of the idea of enhancing personal responsibility for health lies in its intuitive appeal. Holding people accountable (e.g. through requiring higher co-payments) depending on their behaviour is profoundly rooted in a certain interpretation of the liberal principle ‘that the liberty of the individual must be thus far limited; he must not make himself a nuisance to other people.’<sup>9</sup> Following John Stuart Mill, one could thus conclude that – by voluntarily choosing an un-healthy behaviour – certain individuals are damaging the community who, as a consequence, is allowed to withdraw the support normally provided to them according to the solidarity principle. In such instances, withdrawal of support would allegedly be justified if it concerned only guilty risk-takers (such as those who do not eat healthily), since they are not allowed to pass on to their fellow citizens the negative externalities produced by their voluntarily-assumed behaviours, and not risk-carriers, such as people with a genetic

---

<sup>6</sup> S. Huster, ‘Individual Responsibility and Paternalism in Health Law’, in *New Perspectives on Paternalism and Health Care*, ed. T. Schramme (Switzerland: Springer International Publishing Switzerland, 2015), 221.

<sup>7</sup> N. Biller-Andorno & T. Zeltner, ‘Individual responsibility and community solidarity -The Swiss Health Care system’, *New England Journal of Medicine* 373 (2015):2194.

<sup>8</sup> A. Sax, ‘Eigenverantwortung’, *Schweiz Ärztztg* 98 (2017):174. Translation from the German version. The original reads “Leute ohne Eigenverantwortung sind übergewichtig, rauchen und sitzen vor dem Bildschirm, statt sich zu bewegen. Sie essen zu viel Zucker, zu viel Fett und zu wenig Gemüse. Sie foutieren sich um die Empfehlungen der Fachleute und rennen, wenn sie sich krank fühlen, ohne nachzudenken, zum Arzt. Und wir, die schlanken, fitten, sportbewussten Nichtraucherinnen, zahlen mit. Wir, die wir unsere Eigenverantwortung wahrnehmen, werden mit immer höheren Krankenkassenprämien bestraft”.

<sup>9</sup> J.S. Mill, ‘On Liberty’, in J. S. Mill, *Utilitarianism. Liberty and Representative Government*, Introduction by A. D. Lindsay, (London: J. M. Dent & Sons Ltd, 1947), 114.

predisposition.<sup>10</sup> Despite the many doubts that have been cast on such reasoning, the question whether it is appropriate to create policies reinforcing personal responsibility for health has enjoyed ongoing popularity, both inside academia and in the political domain.

In this paper, however, we do not primarily address the theoretical issue of whether it is legitimate to use personal responsibility as a rationing criterion in general. Instead, we focus on the interplay between the principle of personal responsibility for health and the phenomenon of digitalisation in health care. First, we outline how – aside from theoretical arguments for or against this principle – implementing policies based on a strict interpretation of personal responsibility has always encountered the hurdle of *practical enforceability*. We also provide two policy examples to root the debate on a more practical level. Thereafter, we show how digitalisation supposedly offers a remedy to circumvent the hurdle of since it allows closely and accurately to monitor individual behaviour, thus allegedly opening up the possibility to strengthen personal responsibility for health. Based on these considerations, we then analyse the influence of this shift on the conception of personal responsibility and argue that digitalisation stresses the *causal* aspect of this principle. Having highlighted the conceptual and practical limits of such digitally-supported inferences regarding personal responsibility, we finally plead that, beyond a mere focus on the individual, there are more promising alternatives as to how digitalisation can improve resources allocation in health care.

## 2. Personal responsibility for health as a rationing criterion: a practical problem

Using personal responsibility as a criterion for allocating resources in health care remains a contentious idea. On the one side, arguments in favour of more personal responsibility for health underline that de-prioritising patients who contribute to their own poor health is justified on several accounts. It is argued that these patients (1) are more likely to have poor health outcomes following treatment, (2) take away limited resources from patients who are more careful about their health, (3) lack incentives to change their behaviour and (4), if not held to account, may even disincentivise other people to contribute to the financing of health care.<sup>11</sup> On the other side, opponents of the use of personal responsibility as a rationing criterion have argued that ascribing responsibility generates stigma and does not necessarily improve health-related

---

<sup>10</sup> I. Van Hoyweghen, K. Horstman & R. Schepers, 'Genetic 'risk carriers' and lifestyle 'risk takers'. Which risks deserve our legal protection in insurance?', *Health Care Analysis* 15 (2007):179-193

<sup>11</sup> Sharkey & Gillam (note 1).

behaviour, therapeutic outcomes or public finances.<sup>12</sup> Apart from arguments at these two extremes, many authors have tried to find some middle ground. For instance, it has been argued that whether responsibility is prospective (i.e. a commitment to the future) or retrospective (i.e. accountability for the past) should determine its legitimacy.<sup>13</sup> As an alternative criterion, Harald Schmidt<sup>14</sup> has suggested that the degree of consequences (e.g. higher co-payment vs higher co-payment plus lower priority on the waiting list) assigned to the individual would affect a policy's adequacy.

Whilst the theoretical debate concerning the legitimacy of increasing the use of personal responsibility for health as a rationing criterion has flourished, the concrete issues that implementing this principle would entail at a practical level have not received the same attention. It seems clear, though, that using personal responsibility in the rationing of health care would encounter two sets of challenges. On the one hand, it would be necessary to agree upon a list of facts, acts and situations for which responsibility can be demanded and then set the consequences for the individual when those facts, actions or situations occur. Taking the example from Germany quoted above, the policy listed unnecessary cosmetic surgery, piercing and tattoo as triggering actions, and higher co-payment as consequence. On the other hand, it would be necessary to ensure the accuracy and correctness in the concrete operationalisation of such a list. We will refer to these two set of challenges as – respectively – the macro- and micro-level.

At a macro-level, the challenge consists in drafting an evidence-based and socially accepted list of actions for which personal responsibility can be demanded. This entails several questions for policymakers. First, they would need to determine which facts or actions produce a negative outcome *per se* (e.g. does smoking lead to COPD?), or – as Alena Buyx put it – ‘we want to be sure that we know exactly what actions or behaviours lead to a certain condition before holding patients responsible for the consequences.’<sup>15</sup> In this respect, it has been suggested that there are two categories of facts and actions for which people could be held accountable.<sup>16</sup> On the one hand, there are traditional health-related

---

<sup>12</sup> P. Friesen, ‘Personal responsibility within health policy: unethical and ineffective’, *Journal of Medical Ethics* 44(2018):53-58.

<sup>13</sup> E. Feiring, ‘Lifestyle, responsibility and justice’, *Journal of Medical Ethics* 34 (2008):33-36. The exact terminology used by Feiring is “forward-looking” and “backward-looking”. However, the use of “prospective” and “retrospective” is more established in the literature. For a more in-depth definition, see G. Marckmann, M. Möhrle & A. Blum, ‘Gesundheitliche Eigenverantwortung’, *Der Hautarzt* 55 (2004):715-20.

<sup>14</sup> H. Schmidt, ‘Personal responsibility in the NHS Constitution and the social determinants of health approach: competitive or complementary?’, *Health Economics, Policy and Law* 4 (2009):129-138.

<sup>15</sup> Buyx (note 1), 873.

<sup>16</sup> J. Savulescu, ‘Golden opportunity, reasonable risk and personal responsibility for health’, *Journal of Medical Ethics* 44 (2018):59-61.

behaviours like smoking, drinking, and unhealthy eating habits. On the other hand, there are risky behaviours such as practicing extreme sports, opting for elective surgery and driving motorcycles. Furthermore, it would be necessary to determine if those facts and actions truly determine negative consequences for the rest of the society. This would entail both purely economic considerations – e.g. are smokers really compromising public finances?<sup>17</sup> – and moral ones – e.g. would it be socially accepted, in a given society, to require higher co-payments for emergency health care services for drivers?<sup>18</sup> Lastly and more importantly, one would need to determine objective measurements for holding people responsible for a certain fact or action. Is one cigarette a week enough to warrant higher co-payments for health care services? Which health care services exactly will be affected? Only those related to the risk-taking behaviour, e.g. lung cancer treatment for smokers? Or more generally all services, e.g. by requiring smokers to pay higher health-insurance premiums?

Even more complicated are the challenges at the micro-level. In this respect, implementing personal responsibility for health as a rationing criterion would require to ‘single out the one decisive causal factor when it comes to individual patients’.<sup>19</sup> Even when a list of actions and facts and their consequences in terms of responsibility were compiled at a macro-level, the fact would remain that in single cases it would be necessary to distinguish between those individuals where health care services can be rationed due to their behaviour and those where it cannot. Let us consider the example of a rule establishing higher co-payments for treating a multifactorial disease such as type II Diabetes when it is caused by unhealthy habits like exercising too little. Enforcing such a measure as a general policy would require considerable effort to distinguish between those patients who should be held accountable (e.g. because their condition is causally related to specific eating habits) and those with whom society should

---

<sup>17</sup> This aspect might seem a trivial one but cannot be underestimated. For example, it is a common assumption that smokers’ poorer health outcomes generate a higher consumption of health care resources, which would supposedly justify reducing their health care benefits or increasing their co-payments. However, this assumption is often incorrect, from a purely economic perspective. Smokers are often “cheaper” to society because their higher mortality contributes to saving the money that they would have cost the health care and social system had they lived longer, the so-called ‘survivor consumption costs’, see e.g. D.R. Rappange, W.B. Brouwer, F.F. Rutten & P.H. van Baal, ‘Lifestyle intervention: from cost savings to value for money’, *Journal of Public Health* 32 (2009):440-447; L.B. Russell, ‘Preventing chronic disease: an important investment, but don’t count on cost savings’, *Health Affairs* 28 (2009):42-45. Of course, such purely economic considerations ought not to be dominant – e.g. the higher mortality of smokers should not be considered acceptable just because society saves money on their forgone pensions. It is, however, important to consider such aspects before surrendering to the intuitive assumption that it is easy to select those behaviours for which personal and financial responsibility can be demanded.

<sup>18</sup> This aspect is also very important, and it is related to the societal determination of what is considered an acceptable risk-taking behaviour.

<sup>19</sup> Buyx (note 1), 873.

be supportive (e.g. because the illness has occurred due to genetic predisposition). These micro-level challenges concerning the accurate operationalisation of personal responsibility for health as a rationing criterion have been a crucial deterrent to the implementation of policies of this kind. Indeed, an accurate and impartial operationalisation might often prove difficult and especially expensive, thus undermining one of the main objectives why personal responsibility for health would be reinforced (i.e. to save costs). As one author put it, attempts to practically implement policies based on the reinforcement of personal responsibility for health would be largely impractical because of 'the extensive time and resources that would be required to assess each individual's responsibility for a given condition.'<sup>20</sup> For example, with regard to cost-sharing schemes based on personal responsibility in some US states' publicly-funded Medicaid programme, it has been argued that the additional administrative costs incurred by tracking patients would likely exceed expected savings, rendering the implementation financially inefficient.<sup>21</sup> On the same line, other authors have emphasised that, from a concrete policy perspective, 'not all risky activities are taxable (e.g. sitting on the couch all day) since they are not *administratively* controllable.'<sup>22</sup> From now on, we will refer to this set of issues as the problem of *practically enforcing* personal responsibility for health.

### 3. The challenge of *practical enforceability*: two policy examples

The challenges of *practically enforcing* personal responsibility for health as a rationing criterion become even more evident when far-reaching – in terms of people impacted and money affected – policy-questions in the context of rationing are considered. To substantiate this claim, we provide two hypothetical policies: the first one concerning sub-optimal medication adherence, the second one concerning liver transplantation.

Poor medication adherence – i.e. the habit of *not* taking medication as prescribed – has been widely identified as one of the most impactful health-related behaviours – both in terms of health outcomes and financial burden to health

---

<sup>20</sup> Friesen (note 1), 53.

<sup>21</sup> J.B. Wishner, J. Holahan, D. Upadhyay & M. McGrath. Medicaid expansion, the private option, and personal responsibility requirements: the use of Section 1115 waivers to implement Medicaid expansion under the ACA', *Urban Institute*, (2015), <http://www.urban.org/sites/default/files/alfresco/publication-pdfs/2000235-Medicaid-Expansion-The-Private-Option-and-Personal-Responsibility-Requirements.pdf> (accessed September 10 2019). Retrieved in Baker & Hunt (note 1).

<sup>22</sup> K. Bærøe & C. Cappelen, 'Phase-dependent justification: the role of personal responsibility in fair healthcare', *Journal of Medical Ethics* 41 (2015):839 (emphasis added).

care systems. In a famous report by the WHO of 2003,<sup>23</sup> it was estimated that 50% of patients worldwide do not take medications as prescribed. As a result, not only are health outcomes worse, but also considerable amounts of health care resources are wasted. Estimates put the cost of hospitalisations due to poor medication adherence in the range of hundreds of billions of dollars – in the US alone.<sup>24</sup> A putative policy to help tackle this problem could be that of strengthening personal responsibility. If individuals choose not to adhere to the prescribed treatment plan, personal responsibility for such a decision would come into play. The putative policy might require, for example, higher costs for follow-up treatments when individuals incur poor health outcomes as a result of sub-optimal medication adherence. Alternatively, patients could be required to stick to their medication plan as an initial and future-oriented requirement to have their costs covered by the health care system. Assuming that it were possible to define a threshold where patients would be considered non-adherent and assuming that the policy were socially accepted, the problem of *practical enforceability* would remain. In fact, it would often prove difficult to show – when the policy needs to be applied – which patients adhered to their medication plan as prescribed and which did not, thus becoming accountable for the poor treatment outcome. Relying on self-reporting by patients would arguably not represent a fair and feasible solution: with health coverage at stake, lying would be encouraged and honesty punished. An alternative may be checks by medical professionals or administrative personnel verifying the correctness of medication-taking behaviour, e.g. by blood or urine testing. However, this would not only be highly impractical (especially in the outpatient setting) but also financially counterproductive, if the objective of the policy were to save costs.

Another example showing the difficulty of *practically enforcing* personal responsibility is that of liver transplantation. Already in 1991, Moss and Siegler suggested that ‘patients who develop ESLD [end stage liver disease] through no fault of their own (e.g., those with congenital biliary atresia or primary biliary cirrhosis) should enjoy higher priority in receiving a liver transplant than those whose liver disease results from failure to obtain treatment for alcoholism.’<sup>25</sup> According to the authors’ proposal, general guidelines for physicians should not entail an outright ban on liver transplant for people who fail to obtain treatment for alcoholism but simply move them down in the waiting list for transplantation. Their reasoning sparked controversial debates about organ donation and substance abuse, with many subscribing to the intuition that

---

<sup>23</sup> E. Sabaté (ed), *Adherence to long-term therapies: evidence for action* (World Health Organization, 2003).

<sup>24</sup> L. Osterberg & T. Blaschke, ‘Adherence to Medication’, *New England Journal of Medicine* 353 (2005):487-497.

<sup>25</sup> A.H. Moss & M. Siegler, ‘Should alcoholics compete equally for liver transplantation?’, *Jama* 265 (1991):1295-1298.

‘entitlements to health care for a diseased condition are inversely proportional to control and responsibility’<sup>26</sup> – a preference that has also been corroborated by empirical research.<sup>27</sup> More recently, Daniel Brudney has argued in a similar vein that substance abusers are less deserving of liver transplants if they are aware of the consequences, including the fact that they may deprive someone else of a necessary organ transplant.<sup>28</sup> Apart from any considerations about the ethical merit of such proposals, even here the question would remain of how to *practically enforce* this policy in individual cases. As has been pointed out, it is not clear how physicians could ‘distinguish those among this group who could and should have taken steps to prevent liver failure from those who may have had no reason to suspect that their drinking would lead to liver failure.’<sup>29</sup> Whether the reason to ascribe responsibility is rooted in the awareness of the patient (i.e. she is informed about the potential consequences of her actions) or in the presence of a specific link between drinking habits and liver failure, the problem remains that both circumstances are difficult to verify. It seems that the only option would be to ‘undertake intrusive investigations into the private lives of patients.’<sup>30</sup> If responsibility were to be ascribed on the basis of the patient’s awareness of her risky conduct, medical personnel would have to collect evidence to determine such awareness. If, on the contrary, responsibility were to be ascribed on the basis of a specific link between drinking habits and liver failure, doctors would have to impose additional medical examinations (e.g. carbohydrate deficient transferrin (CDT) levels), which would be both expensive and ethically troubling (since they would not promote the welfare of the patients). In either case, this would be a problem, not only by compromising the role of and trust in medical personnel but especially because – at a practical level – it ‘would be a very intensive and time-consuming job to determine the *real* measure of responsibility for a patient’s disease.’<sup>31</sup>

These two examples demonstrate how *practical enforceability* would remain an obstacle to the implementation of personal responsibility in concrete policies. This is because ‘on *practical* grounds, it seems very difficult, if not impossible, to measure out and determine the exact scope of people’s individual freedom

---

<sup>26</sup> W. Glannon, ‘Responsibility, alcoholism, and liver transplantation’, *The Journal of Medicine and Philosophy* 23 (1998):35.

<sup>27</sup> PA. Ubel, C. Jepson, J. Baron, T. Mohr, S. McMorrow & D.A. Asch, ‘Allocation of transplantable organs: do people want to punish patients for causing their illness?’, *Liver Transplantation* 7 (2001):600-607.

<sup>28</sup> D. Brudney, ‘Are alcoholics less deserving of liver transplants?’, *Hastings Center Report* 37 (2007):41-47.

<sup>29</sup> M. Benjamin, ‘Transplantation for alcoholic liver disease: the ethical issues’, *Liver Transplantation and Surgery* 3 (1997):337-342.

<sup>30</sup> *Ibid.*, 339.

<sup>31</sup> W. Martens, ‘Do alcoholic liver transplantation candidates merit lower medical priority than non-alcoholic candidates?’, *Transplant International* 14 (2001):172 (emphasis added).

and responsibility'.<sup>32</sup> Even if theoretical and political issues concerning the appropriateness of using personal responsibility for health as a rationing criterion were set aside, far-reaching policies would always face a thorny dilemma. Either they have to accept approximation and potential errors in those cases where it may be impossible or unreliable to verify the actual adoption of the specific health-related choices to which responsibility is linked (e.g. poor medication adherence, or drinking). Or they require a complex and often costly (especially if needed on a large scale) effort to retrospectively or prospectively check – for example through the presence of specific markers – that individuals have taken the course of action that justifies a different allocation of health care resources.

#### 4. The impact of digitalisation: responsibility becoming enforceable?

Whilst the debate concerning the personal responsibility for health has become increasingly stagnant and repetitive,<sup>33</sup> health care has drastically changed, undergoing a profound digital revolution. Digital health has been defined as 'the development of technological solutions to monitor, process and integrate vast amounts of data at the individual and population levels.'<sup>34</sup> At the core of the digital revolution in health care is a more extensive use of different types of health-related data, which can be divided into three main categories.<sup>35</sup> First, there is traditional patients' information – such as doctor's notes, hospital records and health care bills – which can be collected in electronic form and are therefore often more easily shareable and linkable. In this sense, digitalisation has mainly impacted collection and transit of information, rather than the nature of the information collected. Second, there is the category of data belonging to so called "–omics data streams", which includes genomic and proteomics data now also collectable through direct-to-consumer tests. Third, there is health-related behavioural data traceable through new technological solutions (e.g. mobile sensors on phones, fitness devices or digital therapeutics).

Digitalisation, in other words, has been conveying a true 'datafication of health'.<sup>36</sup> This has fostered views of patients – and individuals more generally – as quantifiable entities that can be defined by the electronic information that

<sup>32</sup> Schmidt (note 13), 130 (emphasis added).

<sup>33</sup> Sharkey & Gillam (note 1).

<sup>34</sup> 'Medicine in the digital age', *Nature Medicine* 25 (2019):1.

<sup>35</sup> M. Swan, 'The quantified self: Fundamental disruption in big data science and biological discovery', *Big data* 1(2013):85-99.

<sup>36</sup> M. Ruckenstein & N.D. Schüll, 'The datafication of health', *Annual Review of Anthropology* 46 (2017):261-278.

is collected from and about them. In the medical literature, it is no minority position to claim that ‘just about everything that makes a human tick can now be quantified like never before, by means of sensors, sequencing, laboratory tests and scans.’<sup>37</sup> At the same time, digitalisation of health care also largely facilitates access to medical data, making patients increasingly transparent. Through electronic health records, wearable devices and other e-health tools, information concerning a patients’ health status – from their medical history and test results to data collected directly through apps and wearables – becomes much more accessible and monitorable. Unsurprisingly, this vision has also been endorsed by a large part of the industry active in the e-health sector.<sup>38</sup> In the most optimistic accounts, digitalisation promises ‘to prevent and mitigate the physical and financial burdens of “lifestyle diseases” such as obesity, diabetes, and cardiovascular disease—conditions that derive from daily behaviours of overeating, underexercising, and smoking—by shifting their management away from hospitals and doctors and into the hands of empowered patients.’<sup>39</sup>

More importantly, with the datafication of health and patients becoming increasingly transparent, digitalisation seems to offer the missing link necessary to *practically enforce* personal responsibility for health. Indeed, the problem of *practical enforceability* gets drastically downsized, since patients’ health status and their health-related behaviours become easily measurable and accessible through digital means. For example, the European Union has recently funded the MyHealthAvatar project, consisting of an internet-platform where citizens can upload their behavioural data (e.g. number of steps), medical records and also allow linkage to their twitter profiles, so that information can be analysed to facilitate the prediction of some non-communicable diseases.<sup>40</sup> Similarly, at the end of 2017, the United States approved the first pill combined with an ingestible sensor that monitors – automatically and in real-time – whether patients take their medications correctly.<sup>41</sup> With the rapid increase of tools of this kind, not only is it possible to ‘deliver a more efficient and effective healthcare system.’<sup>42</sup> but also to effectively monitor patients’ behaviour.

---

<sup>37</sup> L.J. Kish & E.J. Topol, ‘Unpatients—why patients should own their medical data’, *Nature biotechnology* 33(2015):921.

<sup>38</sup> N.D. Schüll, ‘Data for life: Wearable technology and the design of self-care’, *BioSocieties* 11 (2016):317-333.

<sup>39</sup> Ruckenstein and Schüll (note 35), 262.

<sup>40</sup> European Commission, ‘MyHealthAvatar: your digital health status through an app’, <https://ec.europa.eu/digital-single-market/en/news/myhealthavatar-your-digital-health-status-through-app>, (accessed 10 September 2019).

<sup>41</sup> FDA - Food and Drug Administration, ‘FDA approves pill with sensor that digitally tracks if patients have ingested their medication’, <https://www.fda.gov/newsevents/newsroom/press-announcements/ucm584933.htm>, (accessed 10 September 20189).

<sup>42</sup> E. Rich & A. Miah, ‘Mobile, wearable and ingestible health technologies: towards a critical research agenda’, *Health Sociology Review* 26 (2017):85.

Indeed, digitalisation makes it much more appealing to implement policies demanding personal responsibility for health because many risk factors such as a lack of exercise or an unhealthy diet can be easily, extensively and pervasively documented. In a sense, digitalisation has the potential to shift the burden of proof concerning responsibility from society to the individual. If individual-level data is available suggesting that one patient has taken poor health-related choices, this could be used as justification to demand responsibility and, more importantly, as an instrument to make it practically enforceable. The assumption is that the collected data is correct and complete and that the single person – if she wants to avoid responsibility – must prove herself that her poor lifestyle choices cannot be ascribed to her in the single case. When evidence thereof is not provided, rationing health care services covered by the community might become the default option. In the case of medication adherence, for example, patients could be asked to digitally monitor their medication-taking behaviour and, if results show that they miss certain doses, reimbursement of the cost of their medications could be curtailed. In the case of liver transplantation, patients could be asked to prove that they have not been purchasing large amounts of alcoholic beverages or that they have not been frequent visitors to pubs or bars.

The claim that digitalisation provides the means to *practically enforce* personal responsibility as a rationing criterion is not purely hypothetical. Although official policies and regulation of this kind do not exist yet, private actors are already deploying digital health solutions as tools to *practically enforce* personal responsibility for health. In Switzerland, for example, some major health insurance companies are offering customers the possibility to pay cheaper premiums for basic insurance – either directly through discounts or indirectly through monetary rewards – if they demonstrate the achievement of daily challenges in terms of steps or other relevant health-related behaviours.<sup>43</sup> Users simply have to link their fitness trackers to an app provided by the insurance company and, then, those customers who are more active end up paying less for the same insurance coverage than other customers have who are not as fit.

The appeal of using digital tools to *practically enforce* personal responsibility for health is fostered by the logic of personalised medicine. Although its exact definition may vary, the term ‘personalised medicine’ generally refers to ‘a medical model using characterisation of individuals’ phenotypes and genotypes (e.g. molecular profiling, medical imaging, lifestyle data) for tailoring the right therapeutic strategy for the right person at the right time, and/or to determine the predisposition to disease and/or to deliver timely and targeted prevention.’<sup>44</sup>

---

<sup>43</sup> A. Martani, D. Shaw & B.S. Elger, ‘Stay fit or get bit-ethical issues in sharing health data with insurers’ apps’, *Swiss medical weekly* (2019), 149.

<sup>44</sup> Council conclusions on personalised medicine for patients, 2015/C 421/03, <https://op.europa.eu/en/publication-detail/-/publication/L416ce37-248c-11e5-b528-01aa75ed71a1> (accessed 10 September 2019).

In other words, the movement of personalised medicine contends that individual health-related data should be routinely used to improve the care of patients at the individual level by making care more tailored and precise. The same logic could be extended to the use of data at the societal level to personalise and individualise resource allocation in the health care sector. As has been argued, 'it is assumed that more information necessarily will lead to better healthcare and economic efficiencies, both by encouraging patient engagement and self-responsibility for their health and providing healthcare services with the data they need to improve medical care and service delivery.'<sup>45</sup> Beyond promising to solve the practical problem of enforceability, such reasoning also affects the way personal responsibility in health care is construed on a conceptual level.

## 5. Digitalisation and causal responsibility

As digitalisation promises to make personal responsibility for health *practically enforceable*, it is important to reflect on the consequences that this can have on the conception of personal responsibility and its use as a criterion to allocate health care resources.

Throughout the debates about personal responsibility for health care rationing, several attempts have been made to disentangle its different conceptual facets. Gerald Dworkin<sup>46</sup>, for example, distinguished between three interrelated aspects of the concept of personal responsibility, namely role-responsibility, causal-responsibility and liability-responsibility. With regard to health, role-responsibility could roughly be said to refer to a person's responsibility for her health precisely because it's *her* body, of which she has an obligation to take care. In comparison, causal responsibility describes an individual bringing about a certain health impairment as a consequence of her very behaviour. As Walter Glannon put it: 'To the extent that a person has causal control over the events that determine his healthy or diseased condition, he is causally responsible for these events as well as for this condition.'<sup>47</sup> Finally, liability responsibility describes the aspect of holding a person materially accountable for her actions' consequences, such as paying for her own treatment.

While the other two aspects stay largely constant, it seems that increased traceability due to digitalisation in health care mainly affects causal responsibility. This dimension of responsibility focusses on voluntarily assumed risks and 'implicates [that] the individual's choices and actions with regard to diet, exercise,

---

<sup>45</sup> D. Lupton, 'The digitally engaged patient: Self-monitoring and self-care in the digital health era', *Social Theory & Health* 11 (2013):260.

<sup>46</sup> G. Dworkin, 'Voluntary Health Risks and Public Policy', *The Hastings Center Report* 11 (1981):26-31.

<sup>47</sup> Glannon (note 25), 33.

and so forth [help] to determine his or her health status'.<sup>48</sup> In other words, causal responsibility underscores the factual relations between individual behaviour and its consequences, encouraging to hold patients accountable for them. Traditionally, it is particularly this aspect of personal responsibility that has often been subject to moralisation.<sup>49</sup> This is because the underlying claim of causal responsibility is that every individual needs 'to change his personal bad habits or quit complaining. He can either remain the problem or become the solution to it.'<sup>50</sup> From this perspective, linking causal responsibility to culpability, *unhealthy behaviour* equals *bad behaviour*, a problem for which people should be held accountable.

Digitalisation seems to be closely linked to this aspect of personal responsibility and it further extends its scope. By making individual behaviours ever more traceable, digitalisation emphasises the importance of choices with respect to health outcomes – is the patient compliant with her medication regime? Does she eat, sleep and drink well? Has she sought medical treatment at the appropriate time? At the same time, digitalisation advances an allegedly value-neutral conception of responsibility, according to which individuals can be held accountable when objective data confirms they have causally contributed to their poor health. In this perspective, accessible and shareable information concerning the life – both inside and outside the health care sector – of a patient offers a supposedly *objective* benchmark that can be used to define and treat the patient herself. Health-related data is thought of as a repository of all the events and choices that patients have taken and that can have a – direct or indirect – influence on their health.

When the causal aspect of responsibility is emphasised, patients' data can be framed as a useful tool not only to find the most apt treatment for single patients, but also to single out patients for whom health care resources can be used most effectively. As others have argued, there is a – potentially unconscious or implicit – connection between notions such as personalised or individualised health care and responsabilisation in health care policy.<sup>51</sup> Given the wide-spread optimism regarding the objectivity of data and algorithmic decision making,<sup>52</sup> allocating resources based on vast individually and longitudinally collected

---

<sup>48</sup> Minkler (note 1), 122.

<sup>49</sup> R.C. Brown, 'Resisting Moralisation in Health Promotion', *Ethical Theory and Moral Practice* 21 (2018):997-1011.

<sup>50</sup> J. Knowles (ed.), *Doing Better and Feeling Worse: Health in the United States* (New York: Norton, 1997). Retrieved in Minkler (note 1).

<sup>51</sup> R.C. Brown, 'Moral responsibility for (un) healthy behaviour', *Journal of Medical Ethics* 39 (2013):695-698.

<sup>52</sup> P.L., Galison, 'Algorithmic Dream of Objectivity', in *Possible Minds: 25 Ways of Looking at AI*, ed. J. Brockman (New York, Penguin Publishing Group, 2019), 231 et seq.

personal data can be presented as objective, unbiased and therefore even just.<sup>53</sup> This is consistent with the view that ‘digitisation of the welfare state and e-health services is an advancement based on the assumption that more access to information is better for citizens, patients and consumers’,<sup>54</sup> When choices and behaviour are documented through an extensive data-collection effort, holding individuals accountable for those choices and behaviours becomes a seemingly obvious consequence.

The focus on causal responsibility within the interplay between personal responsibility and digitalisation seems to have two further implications. On the one hand, tracking causally relevant health-related behaviour before the onset of a disease further extends the reach of the medical paradigm into the ordinary life of the healthy, in line with the broader phenomenon of medicalisation. In fact, the advent of the new category of ‘unpatients’ – defined as ‘neither patients in the usual sense of being under treatment, nor nonpatients, in the sense of being [totally] free of a medically relevant condition’<sup>55</sup> – had already been prognosticated at the dawn of the genomics era. With digitalisation, the datafication of medicine and the possibility of using data to predict future health status, the ‘sense that some, perhaps all, persons though existentially healthy are actually asymptotically or pre-symptomatically ill’<sup>56</sup> has advanced. Secondly – and more importantly – the reinforcement of the *behavioural* side of personal responsibility caters for a conception of health that is markedly atomistic. The public health dimension of health tends to get lost, and the latter is rather seen as the product of a series of choices by single self-caring individuals. In this perspective, persons are positioned as ‘ready and willing to actively engage in their own healthcare and promote their own health, in the attempt to shift such responsibilities from the state to the individual.’<sup>57</sup> If it is mainly dependent on behaviour, health belongs to the domain of the individual-consumer, with the corresponding need for the (welfare) state to back-off.<sup>58</sup> Indeed, a transition is happening from the idea that ‘[m]y health is the responsibility of my physician [and my health care system]’ to the new thinking that ‘[m]y health is my responsibility, and I

---

<sup>53</sup> In the literature supporting the use of personal responsibility as a rationing criterion, this includes roughly two elements: 1) the idea that only actions which produce a relevant health-related outcome (either positive or negative) would be used to ascribe responsibility; 2) that only those individuals who have autonomously chosen those actions would be held responsible.

<sup>54</sup> A. Fotopoulou & K. O’Riordan, ‘Training to self-care: fitness tracking, biopedagogy and the healthy consumer’, *Health Sociology Review* 26 (2017):65.

<sup>55</sup> A.R. Jonsen, S.J. Dufy, W. Burke & A.G. Motulsky, ‘The advent of the “unpatients”’, *Nature medicine* 2 (1996):623.

<sup>56</sup> N. Rose, *The Politics of Life Itself: Biomedicine, Power, And Subjectivity in The Twenty-First Century* (Princeton, NJ: Princeton University Press, 2007). Retrieved in Schüll (note 37).

<sup>57</sup> Lupton (note 44), 266.

<sup>58</sup> Schüll (note 37).

have the tools to manage it.<sup>59</sup> As a consequence, if ‘health is mostly a function of how individuals choose to behave, then medical care is less important.’<sup>60</sup>

## 6. Enforcing personal responsibility: the best way of using digitalisation to improve resource allocation?

In the previous paragraphs, we have explored some of the limitations that the practical implementation of policies using personal responsibility for health as a rationing criterion has traditionally encountered. We have shown how digitalisation promises to close the loophole of *practical enforceability* by offering tools for monitoring exposure to individual risk factors, thus allowing to hold people accountable for negative health outcomes. In this sense, digitalisation corroborates the often-implicit syllogism that, since many risk factors can be tracked on an individual level and correlate with behaviour, responsibility for health should be ascribed to individuals and their choices. This narrative is in line with the twofold promise of personalised health care which aims at being ‘a stone that kills two birds: its effectiveness is tantamount to its cost-efficiency.’<sup>61</sup> The emphasis on the individual, her behaviour and her own personal responsibility is thus seen as ‘an important contribution to diminishing the burden of disease and financial cost.’<sup>62</sup> From this perspective, even population health is not seen primarily as a collective concern, but as the arithmetical sum of the effort by single citizens to self-manage their own individual health.

However, even if digitalisation seemingly allows the creation of the conditions to use personal responsibility as a criterion to allocate resources, there are several limitations to this proposition. The first problem concerns accuracy. Although digital tools in health care allow monitoring patients (and prospective patients) in a much more granular way, measurement of individual behaviours is still an infant science, frequently rendering the quality of the measured data problematic. Some medical devices – especially wearables – are often commercialised without proper scientific validation, thus raising the question whether ‘it make[s] sense—and is it ethically defensible—to collect and analyse data of questionable accuracy,’<sup>63</sup> especially if such data is then used to determine access to socially funded health care. While if studies on the accuracy and validity of

<sup>59</sup> M. Swan, ‘Health 2050: The realization of personalized medicine through crowdsourcing, the quantified self, and the participatory biocitizen’, *Journal of personalized medicine* 2 (2012):108.

<sup>60</sup> D. Wikler, ‘Who should be blamed for being sick?’, *Health Education Quarterly* 14 (1987):17.

<sup>61</sup> T. Sharon, ‘Self-tracking for health and the quantified self: Re-articulating autonomy, solidarity, and authenticity in an age of personalized healthcare’, *Philosophy & Technology* 30 (2017):100.

<sup>62</sup> *Ibid.*, 100.

<sup>63</sup> B. Sperlich, H. Holmberg, ‘Wearable, yes, but able...?: it is time for evidence-based marketing claims!’ *British Journal of Sports Medicine* (2017):51:1240.

data produced by health monitoring tools have recently picked up,<sup>64</sup> for now, caution concerning data quality is certainly warranted. The second challenge concerns determining causal relations. On a conceptual level, inferences from human behaviour to health outcome remain challenging and often spurious – not least given the complexities of health-related behaviour and the multi-factorial aetiologies of many common diseases. The two policy examples discussed in this paper are cases in point. With regard to alcoholism, debates about the culpability of addicted individuals in the light of their socio-economic circumstances, personal history and biological disposition are long-standing and have even featured in a controversial ruling of the US Supreme Court.<sup>65</sup> Even concerning the supposedly easier case of medication adherence, research shows that medication adherence is as much a function of patient-doctor interaction and the structures of a health care system as it is the responsibility of individual patients. A comprehensive literature review on the topic thus concluded that '[b]elieving that medication nonadherence is the “fault” of the patient is an uninformed and destructive model that is best abandoned’.<sup>66</sup> Third, even if accuracy and causality issues can be surmounted in specific instances, the question remains whether we believe allocation based on personal responsibility to be adequate and ethically justified – especially from the point of view of justice. While it is beyond this paper’s scope to take a general stance here, it seems clear that any answer to this question would need to take the actual consequences of implementing such policies into account.

So, is enforcing personal responsibility for health the best use of digitalisation for allocating scarce resources? While digital monitoring of risk factors such as leading a sedentary life happens at the individual level, this does not necessarily entail that assigning responsibility to the individual is an appropriate or effective strategy to improve health outcomes – or reduce overall costs. Indeed, alternative approaches for using the potential of digitalisation may be better suited to improving resource allocation. Digitalisation allows, for example, to collect data of large cohorts to scale-up epidemiological studies, improve our understanding of the impact of environmental factors on health and study how to ‘make avoidance of behavioural risk factors easier’.<sup>67</sup> Digital tools can also be used to conduct Phase IV post-marketing studies of newly approved drugs,

---

<sup>64</sup> See e.g. E.A. Chowdhury, M.J. Western, T.E. Nightingale, O.J. Peacock & D. Thompson, ‘Assessment of laboratory and daily energy expenditure estimates from consumer multi-sensor physical activity monitors’, *PLoS one* 12 (2017); M.A. Case, H.A. Burwick, K.G. Volpp, & M. Patel, ‘Accuracy of smartphone applications and wearable devices for tracking physical activity data’, *Jama* 313 (2015):625-626.

<sup>65</sup> *Traynor and McKelvey vs. Turnage*. (1988).108 S. Ct. 1372. Retrieved in Glannon (note 25), 39.

<sup>66</sup> M. Brown & J. Bussell, ‘Medication Adherence: WHO Cares?’, *Mayo Clinic Proceedings* 86 (2011):312.

<sup>67</sup> R.C. Brown, H. Maslen & J. Savulescu, ‘Responsibility, prudence and health promotion’, *Journal of Public Health* 41 (2018):563.

to then decide whether it is appropriate and safe to publicly reimburse their costs or recommend their use. Finally, digitalisation can offer the tools to better target public health interventions that extend beyond the individual level such as tailoring suitable limits for pollutants.

## 7. Concluding remarks

Allocation of resources is an intricate matter and developing strategies to cope with scarcity remains a constant challenge for health care systems. In this respect, tackling individual risk-factors that contribute to non-communicable diseases constitutes an important milestone. Digitalisation can indeed support this process. With appeal to personal responsibility, digitalisation may be used to monitor individual behavior to single out the allegedly “undeserving”, whose health care expenditures should not be covered by public means. However, we hope we have illustrated the problems of using digitalisation in this manner. We are aware that neither of the alternative uses of digitalisation we have suggested will definitely settle the problem of resource allocation. But holding individuals accountable for their digitally monitored health most likely won't either. Ethicists, policymakers and society at large should thus revisit old debates about distributive justice in health care and carefully think about the way new technologies are used for resource allocation.

## 8. Abbreviations

COPD= Chronic Obstructive Pulmonary Disease  
FDA= Food and Drug Administration  
CDT= carbohydrate deficient transferrin

## 9. Acknowledgments

A preliminary version of this work was presented by AM during the Autumn Academy 2019 by the Academia Engelberg. AM would thus like to thank all the participants to the Academy for their precious feedback and inputs. The authors would also like to thank Christopher Poppe and Maddalena Favaretto for their comments on previous versions of the paper.