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# Patient Transformers

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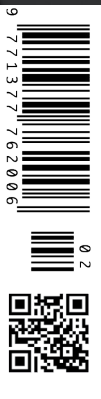
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## Editorial



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# Patient Transformers

Online knowledge, self-help groups and special interest forums have transitioned physicians from almighty omniscient 'demigods in white' to professionals heftily challenged by patients and their Dr Google.

As a result, physician self-reflection and patient participation have become the pillars of modern medical ethics and treatment programmes. Today's empowered patient has the ability to manage their own affairs, take responsibility and share the decision-making power with the physician.

As much as physicians have expertise and authority over matters related to science and disease, the patient is no longer a silent party but a customer who knows their rights.

Our contributors talk about Patient Transformers and how the role of the patient has evolved. As healthcare consumers, patients are demanding better quality, faster care and improved outcomes.

Ian Weissman writes about the prevalence and consequences of health disparity and suggests strategies to solve this crisis. Maria Gutiérrez-San Miguel Guilera talks about the transformation of her hospital in Spain to VBHC, and the challenges and achievements during this journey. Fabian Bolin discusses the power of the patient voice in accelerating cancer care improvement. Begoña San Jose explains how access to patient data can help provide patient-centric care. Sue Farrington covers the importance of patient/citizen participation and access to quality health information. Then, Ton Hanselaar and Matthijs van der Linde highlight problems that can be solved by applying value-based healthcare.

Theresa Rohr-Kirchgraber and co-authors talk about Body Dysmorphic Disorder, and the obsessive and debilitating preoccupation patients have with perceived physical flaws and how this obsession often goes undetected and untreated. Michael van den Berg and Frederico Guanais reflect on the growing interest among stakeholders to transform health systems by putting people at the centre.

Olivia Lounsbury and Donna Prosser highlight how patients and family members are equipped to facilitate involvement in their care. Peter Kapitein questions some of the hyped patient-engagement concepts and the reality of their practical application. Pilar Manchón Gabás talks about patient communication in radiology and its role in strengthening professional relationships and deepening patient engagement.

While patients must be at the centre of all healthcare activities, a balance of power between patients and physicians must be maintained. The transformed, actively engaged individual can help promote patient-centred care. But this can only be achieved in partnership with physicians. Respect, collaboration and harmony will deliver satisfied patients and improved outcomes.

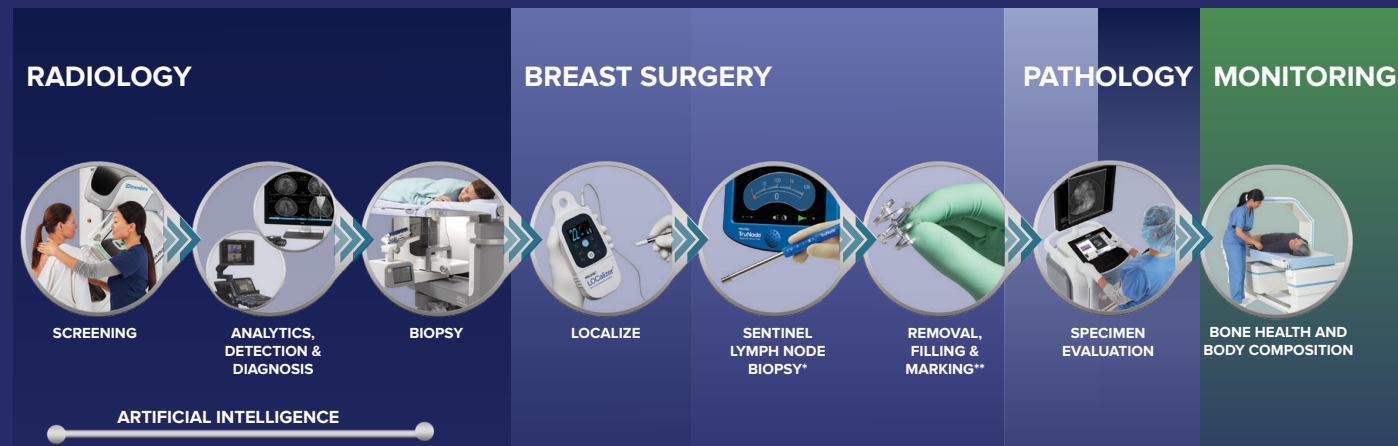
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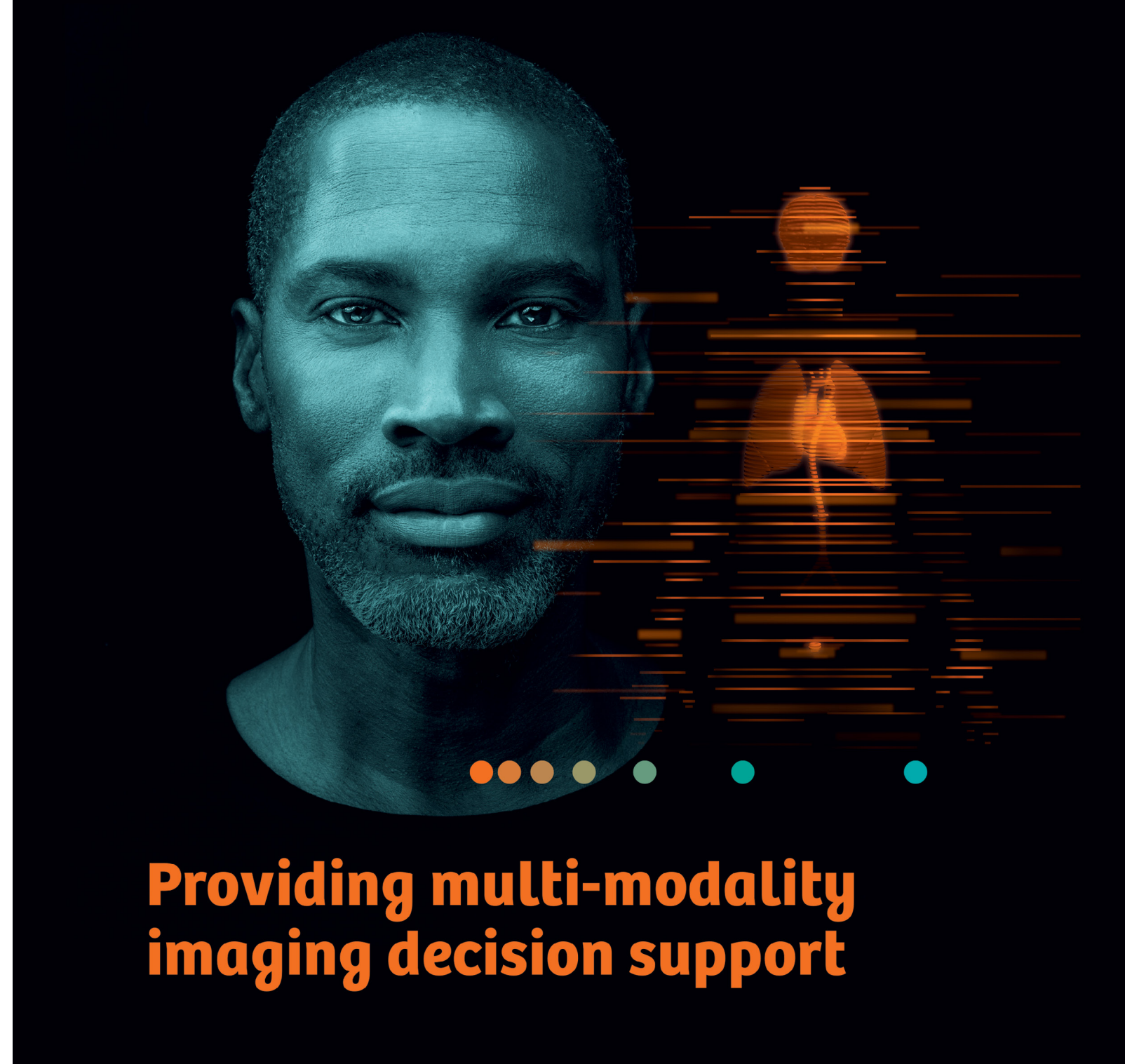
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Today's patient is armed, informed and fully engaged in their care delivery. How does this abundance of knowledge change hospital systems and care delivery? How much is the patient already a care consumer with choices - and is there such a thing as too much choice? What innovative ideas is the market offering to face these challenges? This and much more is explored in this issue.

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# La Grande Finale!

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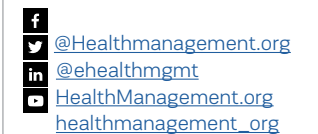
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# Protecting Vulnerable Populations from COVID-19

## Why health governance and operations matter to implement interventions fast. Bavarian perspective

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Elderly residents of long-term care facilities have been among the groups most affected by the COVID-19 pandemic. Like many other countries, Germany and its states have implemented targeted measures to manage the pandemic. Bavaria specifically has taken a coordinated approach to support care homes by setting up a special Task Force Care Homes assisting local authorities and facilities. This report presents a case study on how Bavaria was able to mitigate several implementation challenges in the context of long-term care management. As the second wave of the pandemic is on the rise worldwide, the purpose of this article is to describe measures taken and share lessons from Bavaria's experience.



### Key Points

- The COVID-19 pandemic heavily affects elderly population in long-term care facilities.
- Health governance priorities with clear protocols matter.
- Central support and operations are key to accelerating implementation and eliminating misinformation.

### Background Situation

To date, the COVID-19 pandemic has heavily affected the elderly populations worldwide, leading to a significant number of deaths in people of 60 years and older. Long-term care (LTC) settings, especially care homes, have experienced large COVID-19 outbreaks associated with high fatality rates. International comparisons are still challenging due to

different sources and incomplete datasets, as well as different definitions and aggregation levels. Nevertheless, recent studies have started to shed some light on COVID-19 fatalities linked to LTC settings (WHO 2020; BMSGPK 2020; Comas-Herrera et al. 2020a, 2020b).

Fatality rates among elderly people are significantly higher than among total population in all countries, though the

share of fatalities due to COVID-19 in care homes varies from country to country. Data show that in Germany, Austria or Denmark, the fatality rate is between 0.4% and 0.5% of the total population linked to care homes. In contrast, the share of care home residents dying due to COVID-19 amounts to 4.9% in Belgium, 5.3% in the UK and 6.1% in Spain (Comas-Herrera et al. 2020b).

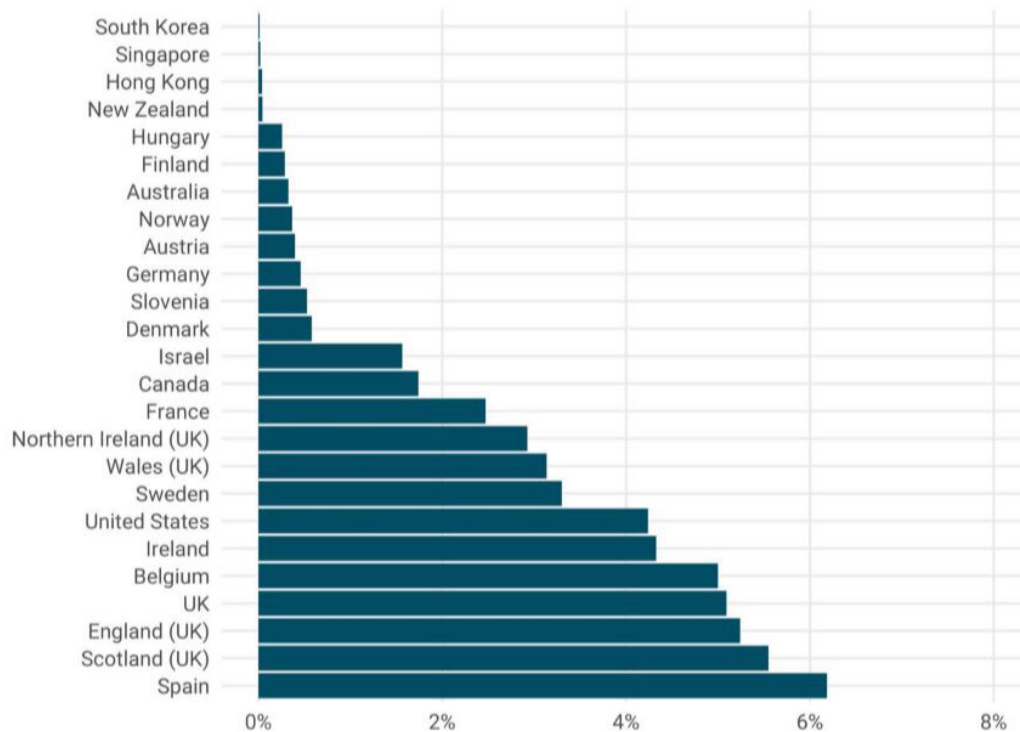


Figure 1. Share of Care Home Residents Whose Deaths were Linked to COVID-19 Compared to the Care Home Population (Comas-Herrera et al. 2020b).

Even more alarming is the fact that in several European countries more than 35% of all COVID-19 related deaths were linked to LTC facilities. In Germany, for example, 35% of COVID-19 deaths have been reported in such facilities; in the US, 45%; in Belgium, 64% (Comas-Herrera et al. 2020b).

The severe impact of the SARS-CoV-2 spread in LTC settings has led to the World Health Organization (WHO) issuing a policy paper, which flags the severe weaknesses in emergency response with regard to LTC services worldwide and outlines key policy objectives to help mitigate the risk of the COVID-19 spread across LTC facilities (WHO 2020).

As it is still very early to make a systematic assessment of the attainment of all objectives, individual case studies can help shed light on different societal conditions and different approaches and strategies of emergency response. Case study examples can particularly help further identify and specify effective approaches that have been proven successful in mitigating the

risk of the spread among residents of LTC such as the elderly or people with disabilities. For instance, countries such as Germany put very thorough measures in place early on in the pandemic to protect the elderly. Bavaria in particular, as one of the most affected federal states of Germany, took a coordinated approach early on to protect the elderly and people with disabilities living in LTC facilities.

As these measures were followed by a substantial drop in the infection and mortality rates in the subsequent weeks of the outbreak, an analysis of the Bavarian example might provide some indications as to which measures to implement the policy objectives identified by WHO have proven effective in mitigating the risk of COVID-19 in a coordinated and timely manner.

This article thus presents the Bavarian COVID-19 strategy towards LTC, focusing on factors that might offer insights into its effectiveness, such as identification and prioritisation of coordinated policy objectives to mitigate the

COVID-19 impact on the elderly through effective implementation structure of interventions.

As the second wave of the pandemic is on the rise worldwide, the purpose of this article is to share the lessons of the timely measures taken in Bavaria so that others could learn from this experience. To this end, the paper relies on a descriptive case study methodology instead of a comparative study at this stage.

### Strategies Against COVID-19 Spread in Care Homes

After the initial rise of case fatalities due to COVID-19 among the elderly worldwide, different institutions started releasing guidelines as early as in February 2020 to provide guidance on how to mitigate the risk of outbreaks in LTC settings. While the initial focus was on the health sector in general, many guidelines subsequently embraced strategies of protecting the vulnerable population in LTC facilities.

For instance, the European Centre for Disease Control (ECDC) has been



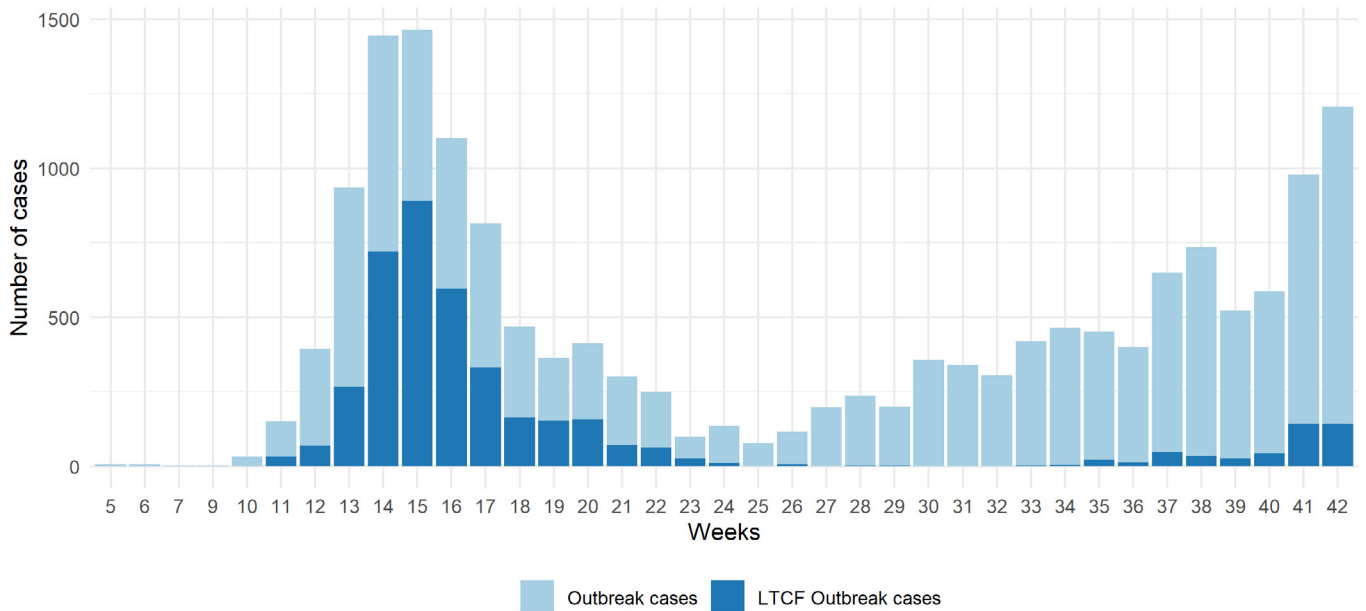


Figure 2. Number of Cases in Outbreaks in Bavaria, 2020, Calendar Weeks 5-42 (Bavarian Food and Health Safety Authority 2020). These numbers only represent the outbreak settings, not individual cases.

publishing guidelines for 2019-nCoV-2 infection control and prevention in healthcare settings from February 2020 onwards. This has been complemented by a technical report for EU/EEA Member States planning to implement monitoring systems at LTC facilities (ECDC 2020).

Similarly, many countries developed individual guidelines for their respective health systems, e.g. in Germany, the Robert Koch Institute (RKI) issued the first version of its 'Notes on prevention and management of COVID-19 diseases in inpatient and outpatient care for the elderly' on 23 March 2020 (RKI 2020). After the first heavy outbreaks in the UK in April, Ladhani et al. (2020) outlined potential strategies for prevention of COVID-19 in LTC in addition to immediate and wider testing, isolation and quarantine for care home workers to avoid the rapid growth of infections. Comas-Herrera (2020a) and colleagues from the International Long-Term Care Policy Network (LTCCOVID) elaborated on these thoughts and introduced the need for COVID-19 response coordination in care homes, highlighting the fast and unanimous response as crucial.

In June, WHO further built on the LTCCOVID work and issued a comprehensive policy paper with 11 policy objectives to mitigate the impact of COVID-19 across LTC, including infectious disease monitoring and prevention but also health governance and health systems resilience (WHO 2020).

### Factors of Timely Response; Health Systems Differences

Although the guidance and recommendations are published by multilateral and supranational health bodies such as WHO or ECDC, the implementation of health measures is always the country or even federal state responsibility, therefore the determining factors for a successful intervention are country and federal state specific.

While there are many similarities across different health systems for *what* to do in terms of protecting the elderly from COVID-19, the WHO policy paper (2020) indicates that there have been significant differences on *how* to implement the measures most effectively within the necessary timeframe.

At the very least, a proper approach would require a collaborative commitment to prioritise timely and focussed implementation, and then a setup of governance structures and implementation measurements, to ensure that priority focus is met in a timely manner.

In the LTC context, the implementation challenges are very demanding. Care homes operate in a multistakeholder setting that involves multiple sectors, different ministries at different levels, as also pointed out by WHO (2020). These are conditions that usually work against timely intervention. Furthermore, care home residents are especially vulnerable to isolation measures, bearing the risk of social and psychological side effects exacerbated by the constraints of external visits and other isolation measures (Sporket 2020).

The following paragraphs outline the Bavarian approach during the crisis. Bavaria was able to overcome part of the implementation challenges mentioned above by introducing several policy objectives that were also recommended by the WHO and thus focussed on both the *what* and the *how*.

Eleven policy objectives to mitigate the impact of COVID-19 across long-term care












1.  Include long-term care in all phases of the national response to the COVID-19 pandemic.
2.  Mobilize adequate funding for long-term care to respond to and recover from the COVID-19 pandemic.
3.  Ensure effective monitoring and evaluation of the impact of COVID-19 on long-term care and ensure efficient information channelling between health and long-term care systems to optimize responses.
4.  Secure staff and resources, including adequate health workforce and health products, to respond to the COVID-19 pandemic and deliver quality long-term care services.
5.  Ensure the continuum and continuity of essential services for people receiving long-term care, including promotion, prevention, treatment, rehabilitation and palliation.
6.  Ensure that infection prevention and control standards are implemented and adhered to in all long-term care settings to prevent and safely manage COVID-19 cases.
7.  Prioritize testing, contact tracing and monitoring of the spread of COVID-19 among people receiving and providing long-term care services.
8.  Provide support for family and voluntary caregivers.
9.  Prioritize the psychosocial well-being of people receiving and providing long-term care services.
10.  Ensure a smooth transition to the recovery phase.
11.  Initiate steps for transformation of health and long-term care systems to appropriately integrate and ensure continuous, effective governance of long-term care services.

Figure 3. Eleven Policy Objectives to Mitigate the Impact of COVID-19 Across Long-Term Care (WHO 2020).

**Regulation on COVID-19 in Care Homes in Bavaria**

Bavarian policies regarding care homes include both stationary care homes for the elderly and care homes for people with disabilities. Bavaria has a population of 126,000 residents and approximately 106,000 personnel in stationary care homes for the elderly. Together with those living and working in care homes for people with disabilities, this adds up to a population of about 150,000 residents and 140,000 personnel (these data exclude the elderly and people with disabilities who are receiving ambulatory

care). After the first wave of infections in LTC facilities and with local health authorities overwhelmed by the pandemic burden, the Bavarian government identified a need for special protection of the elderly and disabled people living in LTC facilities. As such, Bavaria opted for a coordinated and concerted approach and set up a governance and implementation structure with a focus on immediate outbreaks and prevention alike, thus overcoming the disparity of decentralised management during the outbreak peak.

Bavaria did so by announcing Katastrophenfall – the ‘State of Emergency’ (SoE)

on 16 March 2020 (Bayerische Staatsregierung 2020), which allowed for centralisation of the main executive authority for COVID-19 related matters. On 25 March 2020 the Bavarian Infection Protection Act (BayIFSG) was issued, among others (Bayerische Staatskanzlei 2020), complementing the federal Infection Protection Act (IFSG) with specific regulations and guidelines on LTC facilities. For instance, regulations included a complete prohibition of external visits from March to May 2020 and restricted visits until the end of June 2020 to prevent the virus from entering these facilities. Further measures included compulsory preparation and implementation of extended SARS-CoV-2 specific hygiene measures in every LTC facility, such as introducing basic hygiene measures, keeping distancing measures, setting up pandemic zones, and ensuring wearing of protection gear.

In addition, the regulations set out a clear protocol for dealing with outbreaks, such as on introducing protection measures and on testing, tracing and isolating to curb the outbreaks. The authorities updated these on a regular basis (current version: 7. BayIfSMV), taking into account new information.

**Power of Mobile Teams**

What makes the Bavarian approach worthy of further examination is its focus on the coordinated implementation of the regulations. After the first reported outbreaks in care homes that involved striking fatalities, the authorities deployed the Bavarian ‘Task Force Care Homes’ to take action against the outbreaks. It was active from 6 April 2020 until 15 September 2020 and consisted of 75 highly qualified staff seconded by the Health Reporting, Epidemiology and Social Medicine unit of the Bavarian Health and Food Safety Authority (15 staff) and the Medical Service of Health Insurance in Bavaria (MDK) (60 staff). The MDK staff in their regular work are responsible for the quality control in LTC, but that was put on hold due to the pandemic. As such, the two organisations agreed to set up this Task Force.

Compared to other parts of Germany, where MDK staff was also supporting local



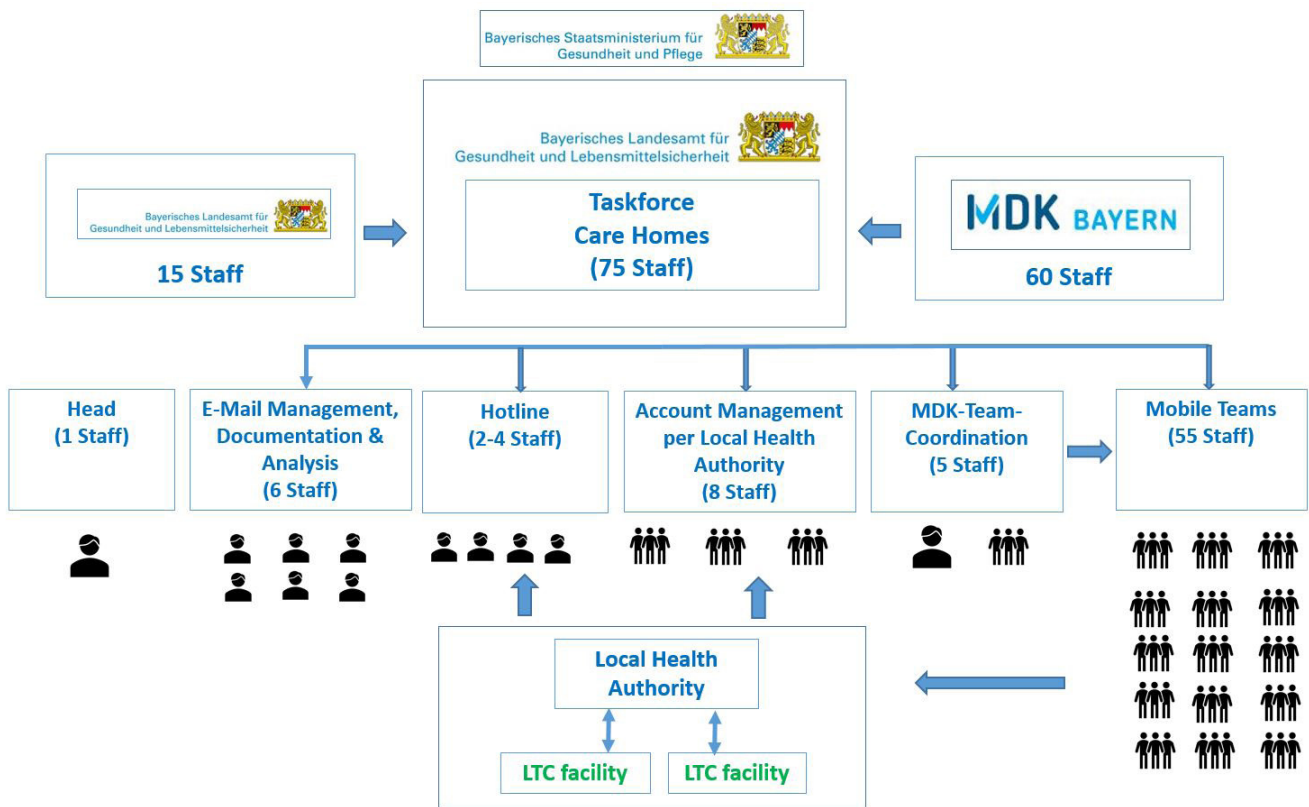


Figure 4. Operational Structure of the Task Force Care Homes.

public health authorities, the Bavarian approach stood out due to its centralised nature. One of the reasons for this centralisation was the insufficient number of health personnel at the local public health authorities to deal with the pandemic.

Overall, the professional background of the team included areas such as Public Health, Medicine, Nursing, Care Home Management, Health Management and Prevention.

The mandate of the Task Force was to protect care homes against further outbreaks and COVID-19 related deaths in cooperation with the local health authorities. For this, it offered telephone and email support to care homes and health authorities, but most importantly, this new unit was able to rapidly put together and send mobile teams to help local health authorities effectively manage outbreaks locally.

When the Task Force was set up, it compiled a list of 2,199 LTC facilities in Bavaria from different sources. For 1,491 care homes out of this total population,

a risk assessment with regards to the severity of SARS CoV-2 outbreaks was conducted, clustering LTC facilities into high-, medium- and low-risk categories. Assessing criteria such as the age of the building or caring for residents with dementia, 759 care homes were considered high-risk, 506 medium-risk and 226 low-risk.

The Task Force offered support to all facilities classified as high- and medium-risk through a telephone survey, but all facilities could also proactively request support.

Based on the risk assessment and the incoming requests, the Task Force supported 1,454 care homes out of 2,199 LTC Facilities (66,1%) within 1,591 missions. Of the 1,591 missions, 561 care homes received telephone consultations, and 634 received an onsite visit only, which included consultations on the proper measures implementation both in relation to an outbreak or as a preventative measure. Residents

and personnel of 257 care homes were tested. Within 141 care homes several missions took place.

As the pandemic brought about dynamic needs, the Task Force responded with the following support:

**1) SARS-CoV-2 Outbreak Support.**

In case of an acute outbreak, a mobile team went onsite to support the LTC personnel and local health authorities, making sure tests were conducted in a timely manner and hygiene protocols were introduced accordingly. For this type of support, the Task Force was in touch with 250 care homes that had a SARS-CoV-2 outbreak, and sent a mobile team to 245 care homes for onsite support. As some care homes had quite severe outbreaks, the mobile teams visited those facilities several times to monitor, advise on and adjust hygiene standards, as well as to conduct several follow-up tests on residents and staff.

**2) Prevention.** As the first wave of the outbreak subsided, the Task Force

started offering preventative consulting services to LTC facilities with a high and medium risk score, to increase preparedness in case of a potential outbreak. During this phase, 1,245 care homes were contacted by phone, to prepare them for a potential outbreak. This offer was taken up by 950 care homes that either received telephone consultations or onsite visits.

The main measures taken through the Task Force to deliver support included:

1. Initiating immediate testing of all residents and personnel so that the local health authorities could pursue contact tracing and monitor the spread of COVID-19 within and around LTC facilities.
2. Ensuring the implementation of hygiene and infection control standards

When the lockdown was eased and admissions of new residents, including those who were discharged from hospital, and external visits were allowed again, there was increased demand for consultations on the latest regulations on admissions, visits, etc.

### **Critical Measures to Mitigate COVID-19 Impact Across LTC**

An internal assessment of the Task Force Care Homes highlights the importance of onsite visits, which made the main difference in tackling the pandemic, particularly because of implementing three measures:

- Rapid testing. As the mobile teams were duly qualified and equipped, tests could be conducted rapidly, allowing for proper diagnostics, contact tracing,

such as including emergency response in the federal regulations, or committing indirect funding to staff running the Task Force.

Although our case study cannot claim a causal relationship, this initial analysis seems to indicate that the outlined principles indeed have an impact on the extent and risks of outbreaks in care homes. It should be noted that Bavaria did not systematically build in Policy 8 (support to families and informal care givers) and Policy 9 (prioritise psychosocial support of people receiving and providing care) within the overall care settings during this immediate response. As Sporket (2020) has indicated, mental health challenges can go along with lockdowns and isolation measures following strict infectious disease management measures.

## Many COVID-19 guidelines subsequently embraced strategies of protecting the vulnerable population in long-term care facilities

according to the RKI and the Bavarian guidelines (i.e. setting up pandemic zones, ensuring protection gear use, etc.).

3. Securing staff and resources in care homes to deliver quality LTC service, even in cases of staff shortages due to infection among personnel.

4. Prevention: (a) from April 2020 onwards, additional focus on preventative phone calls using a standardised protocol; (b) preventative visits to LTC facilities where indicated or requested.

Due to the pandemic dynamic development, the focus of consultations varied over time. At the beginning of the pandemic, in April and May 2020, care homes mainly requested support to implement infection control measures, such as isolation zones, and social distancing measures as well as to train staff and residents to properly use personal protection equipment (PPE).

infection monitoring and breaking the infection chain by local authorities

- Immediate onsite advice and enforcement of infection control measures and hygiene standards to curb further spread
- Supporting preventive measures onsite and strengthening the homes' preparedness for a potential second wave.

These measures are closely interlinked with the WHO policy objectives that have been identified as key factors to protect the elderly (WHO 2020). Specifically, this case study demonstrates that Bavaria was able to introduce the first seven policy objectives out of eleven. In addition to rapid testing, implementing infection control measures and providing preventative measures, the Task Force provided adequate resources including material; it monitored the risk for the care homes and provided immediate and preventative support. This was complemented by measures taken by the federal authorities,

### **Concerted Governance and Implementation**

Considering the above-mentioned success of delivering relevant policy objectives identified to tackle the COVID-19 pandemic, it is worth exploring the key factors that allowed the rapid setup of such an initiative in such a timely manner in the multi-sectoral LTC setting, which would otherwise have taken much longer to implement. Furthermore, what made it possible to efficiently contain the spread of COVID-19 in care homes?

The analysis of the Bavarian case identifies three relevant factors contributing to the impact of the interventions: (1) SoE as legal precondition, (2) free capacity of specialists, (3) highly effective management operations.

**(1) Legal precondition.** With the introduction of SoE, Bavaria put in place a legal mechanism that allowed



for coordinated cooperation across otherwise independent administrative units such as ministries, local councils and alike, and thus enabled cooperation with MDK that was otherwise not possible. According to this law, “(an) Emergency in the sense...(is) an event in which the life or health of a large number of people or the natural foundations of life or significant property is endangered or damaged to an unusual extent and the danger can only be averted or the disturbance can only be prevented and eliminated if, under the leadership of the Civil Protection Authority, the authorities, services, organisations and forces deployed cooperate” (Bayerische Staatsregierung 2020). This mechanism enabled the authorities to initiate a cooperation between the Bavarian State Ministry of Interior, Sport and Integration and the Bavarian State Ministry of Health

and could provide management, technical and other medical support.

**(3) Highly effective health management operations.** The Task Force could only be so effective through the dedication of each contributing individual, as well as through the management structures and operations that were put in place for immediate decision-making and operational excellence that allowed rapid updates. For instance, the Task Force operations included clear responsibilities, holiday covers and key contact points for the local health authorities. Besides, the unit set up clear areas of operations, such as documentation and analysis, mission coordination, mobile team coordination, mobile team missions, and a hotline. These were supported by regular information meetings, an information management system with daily updates, and a process to provide the mobile teams with

included creating an interim specialist unit to protect a vulnerable group following a specific protocol. The most important factors to win time in order to interrupt the infection chain were the ability of rapid testing, immediate onsite advice and preventative measures onsite support.

Even though the results are dependent on the German health system structure, they shed some light on how effective measures can help protect the elderly and people with disabilities.

Moving forward, it needs to be emphasised that the Task Force Care Homes was established as an interim solution on the way to more sustainable support for the elderly and people with disabilities living in LTC settings. To ensure transition to more resilient health systems, more systematic research is necessary, such as a comparative analysis of what

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## Care home residents are especially vulnerable to isolation measures, bearing the risk of social and psychological side effects

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and Care in general, and the Bavarian Health and Food Safety Authority and MDK in particular, all to provide priority support to LTC facilities.

**(2) Free capacity of specialists.** This new unit, the Task Force Care Homes, was comprised of 75 specialists, 60 of them MDK auditors of care homes. Such rapid setup was possible only because of the free capacity of MDK’s highly specialised auditors and the flexibility of the Health Reporting, Epidemiology and Social Medicine unit. The work of MDK in care homes was suspended due to the pandemic so that they could be redeployed for new duties, and they were highly motivated to participate and act quickly within their highly specialised niche. Also, the State Office for Health and Food Safety (LGL) unit reduced or suspended their regular duties while the Task Force was active

PPE. Moreover, the Task Force’s mobile teams were organised in such a way that they could react fast and be at a care home the next day the latest, supporting the facility with PPE where needed and helping with implementing relevant hygiene measures.

### Future Protection of Vulnerable Groups

The COVID-19 pandemic has once again highlighted that elderly and people with disabilities living in LTC facilities are a vulnerable population in need of protection. Public health services worldwide are in charge of protecting people against infectious diseases including COVID-19. While there is a global understanding on the necessary objectives, the views on their timely implementation vary greatly. This case study exemplified the Bavarian approach to tackle the pandemic, which

measures different countries took, what went well and what went wrong.

Future research could look into the situation in care homes, both in Bavaria and in other parts of the country, that did not get this concerted support. Also, more international research and policy action is recommended to ensure both short-term and long-term response to the virus. Specifically, the study recommends focussing on the following three aspects:

**1)** WHO has recommended to also prioritise the psychosocial well-being of LTC residents and their families. This was not taken into account by the Bavarian authorities in the beginning, however, as it is outlined in the text, first observations indicate that mental health challenges may be caused by lockdowns and isolation measures following strict infectious disease management measures (Sporket 2020). To ensure keeping vulnerable



groups mentally healthy, mental health risks have to be better researched to empower policymakers with the right ways to ensure that the elderly are not put under additional psychosocial pressure.

**2)** One of the reasons for setting up the Task Force Care Homes was the inability of several local health authorities to cope with the massive spread of infection due to staff shortages. To ensure long-term coping capacity of the local authorities, ways have to be explored to strengthen the public health services in the long run, for them to be able to fulfil their duties (Kuhn and Wildner 2020).

**3)** Similarly, the entire LTC sector has been exposed to this risk because of its many shortcomings (staff shortage, low wages, etc.). As with the public health services, there is a need to explore the care sector pathways, to strengthen the system – if we want to build long-term resilient health systems.

Independent of this research outlook, the future mitigation of the spread of COVID-19 in LTC will depend on the consequent implementation of thorough hygiene concepts on the local level.

### Conflict of Interest

None. ■

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# Enterprise Imaging and Shared Workflow

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The role of a radiologist is becoming more central to healthcare. Radiology departments are overloaded with work. Demand for fast imaging results and 24/7 availability are also consistently increasing. Agfa HealthCare has developed a shared reading workflow within its Enterprise Imaging platform, which allows radiologists to share tasks and expertise beyond the hospital walls. HealthManagement.org spoke to Johan Hendrickx of Agfa HealthCare to find out how the shared workflow feature works and how it can benefit both radiologists and patients.



## Key Points

- Shared workflow refers to the possibility of organising the acquisition of images and their reporting across different sites.
- A shared workflow solution includes access to the entire medical imaging record and reports.
- A shared workflow allows radiologists at different sites and facilities to receive reading tasks based on their expertise.
- A shared workflow is an efficient way to organise the available resources available within a region.

### ***Can you please tell us something about Enterprise Imaging and the shared workflow feature?***

Shared workflow refers to the possibility of organising the acquisition of images and their reporting across different sites. Radiologists can get tasks assigned to them irrespective of where images have been acquired within the region. A shared workflow solution includes access to the entire medical imaging record and reports. Therefore, you have very easy access to all priors, wherever they have been acquired in the region you have set up for collaboration. A shared workflow allows radiologists at different sites and facilities to receive reading tasks based on their expertise.

### ***What is the difference between shared workflow and teleradiology?***

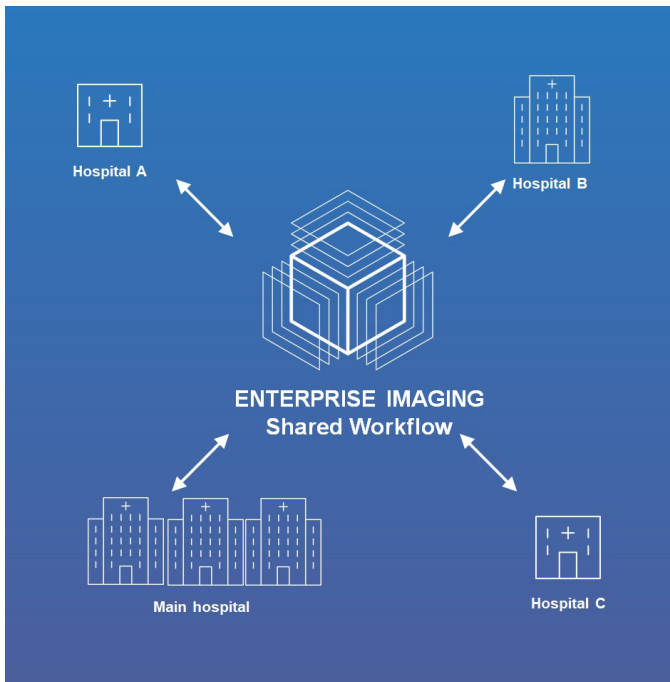
Teleradiology is often used when there are not enough radiologists available to manage the workflow. In this situation, some of the work is outsourced to a third party. Studies are sent to outsourced radiologists, and you wait for them to provide a report. Teleradiology is more of an external collaboration: you push studies to outside radiologists for them to be read or report. One wants to avoid using too much teleradiology because these services tend to be quite expensive.

On the other hand, a shared workflow is a more efficient

way to organise the available resources you have within your region. It allows hospitals to set up cluster sites and collaborate with them so that the work can be more efficiently organised. Unlike teleradiology, it offers a much closer collaboration, as if you're sharing with a colleague sitting next to you. But in this case, they may be in another hospital altogether. Also, with a shared workflow, the process of reading and reporting is faster because if one radiologist is busy or unavailable, another radiologist within that network can handle the reading. Therefore, it allows a facility to have an efficient radiology department 24/7.

### ***Many countries are facing a shortage of radiologists, and it is becoming difficult to manage increased workload. How can shared workflow help solve this problem?***

That is one of the main reasons we built this feature - to allow radiologists to collaborate more efficiently. Shared workflow allows you to share the workload with multiple sites, and you can build workflows around that. Even if there is a need for specific subspecialties, you don't necessarily need such a radiologist on site. You can group that work and push it out towards other sites of your collaboration. Someone with that particular expertise on the other site can pick up



that study, read and prepare the report, which will go back to the site of origin. This is all done automatically, allowing the process to become much more efficient. Specifically, for countries where there is a shortage of available radiologists, work can be organised in a much more efficient way. Not only can you share expertise, but you can also reduce the cost of having to outsource some of this work elsewhere. Hence, shared workflow allows you to use the available resources in a more efficient way.

***Radiologists are also faced with the challenge of controlling costs. Can a shared workflow facilitate this goal? If yes, how?***

Absolutely. With a shared workflow, you do not have to outsource work to external companies that will do the reading for you. It allows you to become more efficient as an organisation, and thus, you drive down the overall cost of that outsourced work.

***If you were to list the key advantages of a shared workflow, what would those be?***

The biggest advantage of a shared workflow is the ease with which you can create and share tasks. Enterprise Imaging is the backend solution. It allows you to create task lists and assign them to specific radiologists or specific groups of radiologists. Radiologists within the network can automatically see tasks assigned to them locally.

Another big advantage is how data is managed within the system. Data is never copied from one site to the other. It is always streamed. If a radiologist wants to open a study for reading, the images of this study will be streamed to them. As soon as they make the report and sign it off, the report is

automatically stored back into the site of origin, so there is no duplication of data.

To summarise, with a shared workflow, no data is moved around, you have full control of the workload, even when it's made accessible remotely, and given distribution of workload is fully automatic, you don't need to have additional workers in place to be able to share.

***Can shared workflow help patients in remote areas?***

Yes, patients can go to the nearest hospital, and even if the radiologist that has the experience to report that particular case is not on site, images can still be acquired in the remote sites. By putting in place a shared workflow, the request can automatically be routed towards the site that has the experience set. The reporting is done there, and the result is forwarded back to the remote or rural side. Hence, with shared workflow, patients do not have to travel to the more specialised centres to get better service.

***How does this feature ensure that there is no duplication of effort and images are not read or shared by multiple people within the network?***

This is actually an advantage that we also implement already with the Agfa HealthCare XERO Exchange Network. All radiologists within the region always have full access to the entire medical imaging record of the patient. If the patient was in another site where a specific study was already acquired, you don't have to redo that acquisition. The fact that you have such easy access to the entire medical imaging records can help avoid duplication.

***Is this a standardised solution, or can hospitals and radiology departments customise the shared workflow feature according to their needs?***

The Agfa HealthCare shared workflow solution is highly customisable. You can design it to match your needs, whether you want to be able to share studies after hours, or during weekends, or weekend days, or for a specific specialty or a combination. You can also ensure quality control by initiating a multi-author workflow for studies that are more difficult. There's a whole range of possibilities that can be put in place. You have total control over the workflow.

***It is clear that radiologists can benefit from a shared workflow. How does it help patients?***

First of all, by making the entire region more efficient, a shared workflow ensures that a particular study is reported faster. Based on this, patient follow-up can be organised at a quicker pace. Shared workflow also increases the flexibility for patients to go into the local hospital, have their images or study acquired there, and benefit from the knowledge and the specialisation over the entire region. After all, this is why we do this – to provide better patient care. ■





# COVER STORIES

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# The Serious Public Health Consequences of Health Disparity: Strategies and Solutions to Solving This Crisis During the Age of COVID-19

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As hospitals and clinics rebuild and reorganise from the public health and financial challenges of the ongoing coronavirus pandemic, there has never been a better time to address health disparity in medicine. The American College of Radiology is collaborating with patients and other health care organisations, to develop solutions to eliminate health disparity and improve the care of all patients.



## Key Points

- Public health systems have never been free of disparity in medicine. This has come into the spotlight even more during the COVID-19 pandemic.
- As COVID-19 continues to rage havoc across the globe, it has become clear that certain patient populations are affected at a much higher rate.
- Health inequities run deep into nearly all areas of healthcare – from maternity care to chronic health conditions to clinical research.
- The American College of Radiology and other professional medical organisations are also addressing the issues of health disparity, and are working on developing solutions.

The U.S. public health system has never been free of health disparity in medicine despite continued efforts over several decades to solve this critical issue, but it is the COVID-19 pandemic which has shined a bright spotlight on this (Bassett et al. 2020).

As rapidly increasing numbers of people in the U.S. and across the world continue to become infected with COVID-19, with many dying, it is becoming clear that certain health populations are being affected at a much higher rate. A recent CDC study found that more than 75% of children dying from COVID-19 are minorities, a finding that is also reflected in death rates among adults (Wan 2020; Fisher 2020).

While urgent action is needed during COVID-19 to save lives, health inequities run deep into nearly all areas of health care from maternity care (Snowbeck 2020; Barrett 2020), to care of chronic health conditions like diabetes, heart disease and cancer (Cooney 2020; Flowers 2020;

Rodriguez 2020), to health inequities in research ranging from drug trials to neuroscience research to COVID-19 vaccine research (Girten et al. 2020; Hamilton 2020; Zenooz 2020).

So what are some successful strategies to solving health disparity? Some of the most powerful strategies have started as grassroots initiatives by individuals. Research centres, private companies and government are also contributing to solving health disparity. Here are some examples.

Dr. Stanford, a Black paediatric surgeon in Philadelphia (USA) noticed that black people were contracting the coronavirus, at nearly twice the rate of their white counterparts, and dying from COVID-19 at higher rates. She also started hearing from Black friends that they were unable to get tested for COVID-19 and were being turned away. Dr. Stanford started recruiting volunteers among the health care professionals in her network, and she formed the Black

Doctors COVID-19 Consortium (BDCC 2020) to test more than 350 people per day in her area. To date, BDCC has tested more than 10,000 people in Philadelphia and the surrounding regions (Feldman 2020).

Dr. Upshaw, a Black biomedical engineer, from Atlanta (USA) recognised the importance of vaccines in preventing disease, but she also recognised America's history of non-consensual medical experimentation on Black Americans which has caused a wide mistrust in the Black community toward volunteering for research trials. Dr. Upshaw is one of the first two Black participants in Moderna's first 45-person COVID-19 vaccination trial. She is sharing her experience with the Black community, and is putting out a message that the vaccine is safe. She is hoping that her positive experience will encourage others in the Black community to volunteer for research trials (Barnes 2020).

New York Genome's Center two-year-old initiative called Polyethnic-1000 (NYGC 2020) is providing cancer research grants dedicated to deepening the understanding of the contributions different ethnicities make to the incidence and behaviour of cancer. This research is bringing genomic innovation to patient populations generally under-represented in research and hence deprived of the benefits of scientific progress. One of the goals of this research is to improve outcomes for a diverse group of patients (Goldberg 2020).

Boston Scientific has a long-running health disparity programme called "Close the Gap" which uses data from

Another solution that has been proposed is providing reparations to disadvantaged communities to end health disparity (Bassett et al. 2020). Reparations would focus on expanding the extremely limited health resources available to minorities. Better neighbourhoods, better schools and access to clean air and water are all tied to improved health care. Addressing issues of stress in minority communities would improve overall health. Addressing and eliminating food security in disadvantaged communities is critical (Santhanam 2020; Silva 2020). These interventions would require a long term commitment over many generations, and currently across living generations to immediately improve public health and reduce health disparity (Sullivan 2020; Fortier 2020).

The American College of Radiology and other professional medical organisations are also addressing the issues of health disparity, and are working on developing solutions.

The American College of Radiology, in addressing population health issues, recently collaborated with the American Medical Association during a recent population health management webinar on health equity (September 20, 2020). During this webinar, several solutions were discussed (American College of Radiology 2020). Joseph Betancourt MD, MPH (VP and Chief and Inclusion Officer at Massachusetts General Hospital [USA]), proposed several solutions or lessons required to improve health equity during COVID-19 and beyond:

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## We must improve health care and eliminate health disparity ...patients are at the centre of care

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public sources like Medicare and private sources like Truven Health Analytics MarketScan to produce statistics on disparity of care. They are focusing on detecting health conditions such as peripheral artery disease which affects Black men and women in greater numbers. Their programme focuses on educating the public and medical community (Carlson 2020).

The state of California (USA) has introduced a "health equity metric" that will require large counties to bring down the spread of COVID-19 in disadvantaged communities that have been hit harder by the pandemic before these counties are allowed to reopen. Dr. Ghaly, the state's health secretary said, "We can't allow transmission rates to so disproportionately impact those communities without significant effort to reduce that disparity and reduce the burden on those communities" (Taxin et al. 2020).

**Lesson 1:** We need to incorporate an equity analysis into emergency preparedness. That is, communities of colour were hit early and hard during the pandemic, and due to health inequities in diagnosis and treatment they suffered disproportionately relative to the general population.

**Lesson 2:** We need to incorporate a race/ethnicity measurement in all we do. That is, improving surveillance and monitoring of disadvantaged populations is critical. Developing dashboards and analysing the results can act as a catalyst for change.

**Lesson 3:** As we redeploy for emergencies, language is an asset. This requires multilingual registries, care groups and trusted messages/messengers. Diversity is critical to making this effective.



**Lesson 4:** As we evolve clinical care, we need to assure equity. This requires multilingual hotlines, patient information, virtual health, and maximising the use of the electronic health record to improve the care of diverse health populations.

**Lesson 5:** We need to care for those within our walls (and institutions), and communication is key. Democratising information is a quality/safety issue.

**Lesson 6:** Social determinants of health will always worsen in the case of disasters, and will hasten spread of disease. Community health needs to take a “doorstep to bedside” approach.

**Lesson 7:** We must have equity in all efforts.

As Dr. Betancourt discussed, leveraging technology and improving communication through clear language is critical to improving care. Arun Krishnaraj, MD, MPH (Vice Chair of Quality and Safety at the University of Virginia [USA]), is using technology to improve communication for patients. He is using procedure-specific videos, rich in animation with clear language, to explain procedures to older patients and non-English speaking patients. This has improved communication for the patient, and has resulted in a better understanding of their care.

20% of the U.S. population speaks a language other than English at home so this is a daily challenge in providing optimal care to patients. Improving communication is critical to obtaining an accurate patient history, explaining a procedure to a patient, requesting consent, and collaborating with a patient on their treatment. Improved communication increases patient satisfaction, and is one of the fundamental principles of patient-centred care (Nickel et al. 2018).

Dr. Kirshnaraj shared a story from Dr. Vanni Rodriguez, an Emergency Medicine resident from Harvard University (USA) where she said, “Gotta love it when they a call a patient altered “mental status”, then you go and chat with them in Spanish and they give you a history...like he’s not altered, he just doesn’t know English.”

Andrea Borondy-Kitts, a retired aerospace engineer, aerospace executive, and a strong patient advocate, who works closely with physicians suggests that radiologists are well

positioned to lead the effort to reduce the health disparity gap. She says that “Radiologists are tech-savvy, have developed strong patient advocacy networks, and are involved in the full continuum of care.”

Other organisations like RAD-AID International (a nonprofit organisation dedicated to improving and expanding radiology services in the developing world and poor areas) are forming collaborations with private industry and public health advocacy groups such as the Black Women’s Health Imperative (an organisation formed out of a need to address the health and reproductive right of African American women) and national patient advocacy committees such as the American College of Radiology’s Patient and Family-Centered Outreach Committee to deliver innovative multidisciplinary women’s healthcare, including public health outreach, nursing and community navigation, breast and cervical cancer screening, radiology, and other medical services to women of colour in the United States (RAD-AID Intl 2020; Black Women’s Health Imperative 2020; American College of Radiology 2020).

These are examples of health care organisations collaborating with private industry and patient advocacy groups to reduce health disparity and improve patient care.

The American College of Radiology has been closely working with patient advocates, such as Andrea Borondy-Kitts, to improve health care and eliminate health disparity since patients and families’ best understand the challenges that they face, and they offer a critical perspective to improving care. Patients **are** at the centre of care (NEJM Catalyst 2017).

As hospitals and clinics are rebuilding and reorganising from the public health and financial challenges of the ongoing coronavirus pandemic, there has never been a better time to reach out to underserved communities to offer them the same level of health care offered to the general public.

The time is now to address health disparity in medicine, and the American College of Radiology is collaborating with patients and other health care organisations, such as the American Medical Association, to develop solutions to eliminate health disparity and improve the care of all patients.

### Conflict of Interest

None. ■

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# Building a Blueprint to Implement VBHC at Operational Level

**Interviewee:** [Maria Gutiérrez-San Miguel Guilera](#) | Coordinator of the Process Unit – Quality, Processes and Innovation Department | Vall d’Hebron University Hospital | Barcelona | Spain

Vall d’Hebron University Hospital is one of the largest hospitals in Spain and one of the most prominent examples of a value-based healthcare institution in Europe. An expert behind the hospital’s VBHC transformation shares the ongoing experience of assessing and redesigning the care cycle based on the VBHC model and outlines the main challenges and achievements on the way.

## **There is no consensus on what value-based healthcare is. How is it understood at Vall d’Hebron Hospital?**

There have been so many concepts linked to the philosophy of value-based healthcare (VBHC). The definition of Value according to Prof. Michael Porter is the Outcomes that matter most to patients divided by the Costs of the care process. Nevertheless, when it comes to implementing it at the operational level, patient needs (thus, value) vary within the same clinical condition. One cannot help wondering how exactly we measure the outcomes that matter most to each patient (once the basic outcomes, such as survival, are assured), how we calculate the cost of the optimised process in a personalised manner.

Vall d’Hebron Hospital (VdH) has developed a methodology that aims to put as the main goal what each patient defines as value. For that, we need to find the root cause of all the clinical activities that don’t add value to the patient, and to erase them from the pathways so that we can reallocate the resources to the activities that do add value to the patient, and, as a consequence, increase Value.

The VdH’s methodology to implement VBHC focusses on four root causes: the optimisation of the process, the consolidation of the safety culture, the enhancement of innovation from the frontline professionals, and the assurance of the clinical practice appropriateness. The continuous improvement of these four concepts will be one of the drivers that work towards the increase and decrease of respectively the numerator and the denominator of Prof. Porter’s formula.

The other driver to systematically increase the value provided to the patient is their engagement/empowerment. When process is being redesigned, we ask patients about their feelings and met/unmet needs through their care process, so that we can together design the tools to enhance engagement and shared decision-making.

Measuring outcomes is crucial as it will be the ‘snitch’ that can tell if patients are getting value in a tangible, routine manner as well as be the driver to culturally root the PDCA (plan-do-check-act) concept at the everyday, operational level.

Costs are the reflection of each patient process and, despite the difficulties we have with measuring these in our organisation, we think the denominator should vary according to the measures embedded in the care process continuous improvement, as this will let us leave aside the costs linked to safety issues, process inefficiencies or inappropriateness of the clinical practice, and only include costs linked to value practices.

## **What specific challenges has VdH had to overcome during its transition to VBHC?**

Where do I begin!.. The real challenge behind these two drivers is the *cultural change* for all the stakeholders of the care pathway that implies VBHC implementation, which is understood and faced differently by both patients and team members dealing with a clinical condition. Reminding that patient value is common ground through the change process is important.

Some specific challenges we’ve found rooted in the culture at the operational level are breaking the ‘silos’ way of working (meaning that each stakeholder knew their own duties but not the ones of another team member treating the same patient); understanding the real potential of the patient outcomes as a tool to personalise the value given to each patient instead of ‘one more task that I have to do’; ownership of process redesign by the frontline team members (who were used to a hierarchy culture, in which all decisions had to be led by ‘the top of the pyramid’); believing that VBHC had to go hand in hand with assigning more resources instead of methodologically detecting where the non-value in their care pathways was, so that



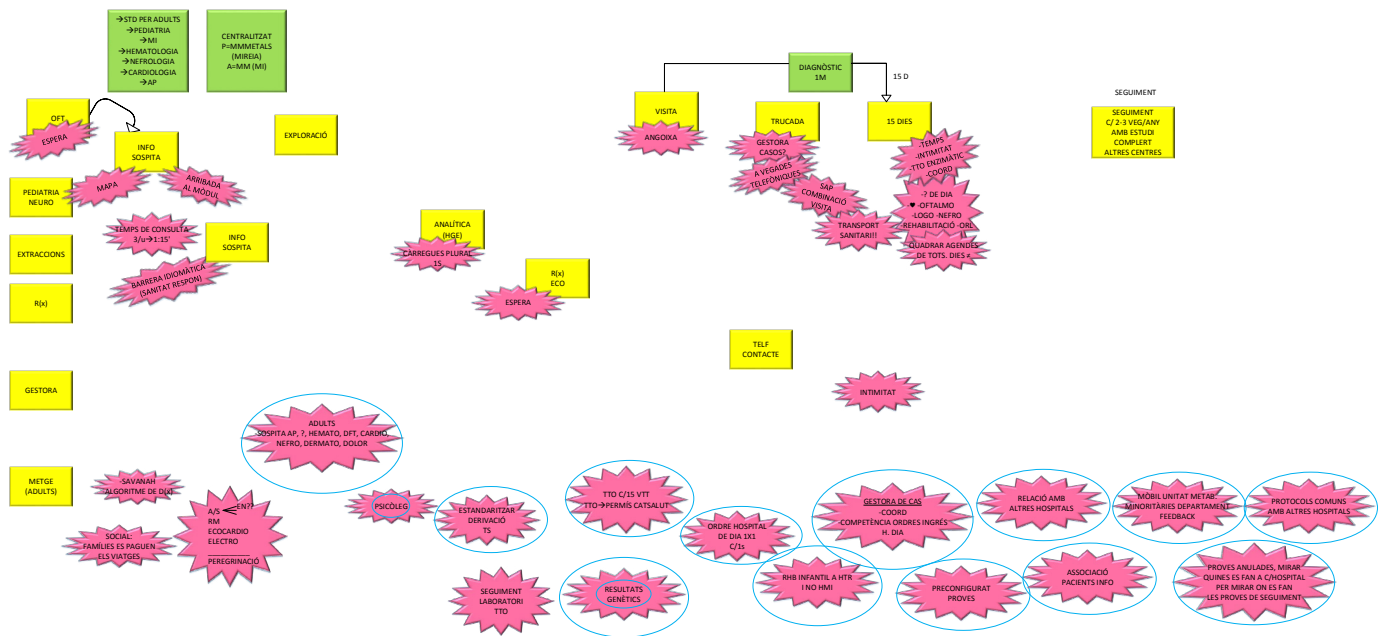


Figure 1. Value Stream Map for Lysosomal Rare Diseases Pathway. The focus was on redesigning the pathways towards eliminating the identified Non-Value Practices: coordination with primary care, coordination among the specialists of the hospital, transition to adulthood, etc. For a full-size image please click [here](#).

those resources could be reallocated; or extracting and analysing data, since data were stored in ‘silos’. Overcoming these challenges is an everlasting work in progress.

If we zoom out a bit from the frontline team members, another challenge could be the extrapolation of the VBHC implementation to ‘non-care’ departments of the hospital. Still at the conceptual level, for example, Human Resources could play a role in this cultural change, as the methodology for job requirement definition can be reoriented towards going beyond the clinical skills, to also include the ‘value skills’ identified for each clinical condition. Similarly, Teaching Departments in university hospitals/institutions can also play an important role by incorporating the VBHC model and its practical applications in the practitioners-to-be learning programmes. Those are yet to come through at our hospital.

All in all, let’s say that ‘it’s always been done this way’ plays an important role for all the stakeholders when talking about challenges.

### What were the first steps you took?

The first step to be mentioned was the full convincement from the Board of Directors to implement VBHC at the hospital. This leadership was essential to communicate to all the teams that VBHC was the key point of the hospital’s growth strategy.

For the VBHC implementation, a management team with a variety of profiles (doctors, nurses, engineers, etc.) was formed. It began with redesigning the care process, identifying practices that didn’t add value, and enhancing those

that did. We started with those treatment units’ processes that were ‘common ground’, such as OR, ER, inpatient wards, etc. A blueprint was developed gathering identified best practices to enhance cultural change among professionals so that they could own these changes. It was the key element of the transformation.

A year passed, and we started working on the outcomes. We introduced the patient-reported outcome measures (PROMs) as a tool to make patient needs the driver for change in the professionals. In addition, primary care was incorporated in most of the working teams. Due to that, the blueprint was redesigned so that outcome measurement and cost calculations among others were added. It should be noted that some of the activities included in the blueprint have not been developed yet at the operational level, as we need to go step by step and learn along the way.

The blueprint has been evolving ever since as we keep on identifying the best practices for cultural change to implement VBHC.

### In the beginning, VdH conducted a comprehensive analysis of the existing cycle of care. What tools did you use?

Our primary blueprint was supported by five to six sessions per clinical working group led by the management team, with the aim to empower them to lead the transformation within their units. The content of these sessions was adjusted to the group needs but mainly included training sessions on process redesign, Value Stream Mapping,



Figure 2. Localised Prostate Cancer Team Building the New Standard of Care.

cross-observation among professionals, a patient session, a development of the new working standard session and implementation of the improvement projects (Figure 1).

#### **What were the top organisational inefficiencies/low-value activities you discovered and how did you address those?**

The top non-value tasks are under the umbrella of coordination with primary care and between specialists at the hospital. These lead to information contradiction, duplicate testing, unnecessary patient and staff trips, increased waiting times, etc.

Building a new standard of clinical pathway implied creating a consensual evidence-based way of working, where all the stakeholders are represented. Normally they all need to lead the change in their units to adjust to the agreed standard, so the Deming cycle (PDCA) is set up (Figure 2).

Optimally, the process (and its changes, both current and future, resulting from continuous improvement) should be represented in the enterprise resource planning (ERP) of the institution so that the wedge in the PDCA cycle can be reaffirmed.

#### **What kind of training did the staff require?**

There are several training sessions held along our blueprint. The very first session that we carry out with clinicians is on process redesign, safety culture and clinical practice appropriateness. Here the tangible outcomes are the technical concepts and the intangible outcome is 'breaking the ice' among professionals of all profiles, who work in different buildings but treat the same patients. The teaching methodology for this is case-study based, and trainees participate in role playing in a very practical and dynamic way.

Next, a training session on the outcomes definition and potential uses is performed with the clinical team, right before the session with the patients, so that the methodology is given to transform empathy into a standardised way of measuring and working.

Right after this session comes the one with patients, led by the Citizen Care Department. With the help of an Empathy Map and a Journey Map (Figure 3), we learn about the patients' experience through their care processes as well as the unmet needs they indicate. In the future, these sessions aim to also be a tool to identify a patient representative for each clinical condition and to incorporate them in the continuous improvement teams.

#### **Patient education and training is named as one of the important elements of the VBHC strategy. How do you address this aspect?**

During the sessions with patients, we distinguish different profiles that require different approaches. Improvement projects towards patient education and training to enhance engagement are being developed. For example, in the stroke and neurotrauma clinical pathways, patients have a visual management tool so that they can anticipate their daily agenda and discuss their therapeutic goals. Another example is a visual management board for paediatric solid organ transplantation, engaging kids to adhere to their treatment and healthy lifestyle.

We think this is just the first step on a long way. During the sessions with patients, we already feel like identifying those who in the future might be integrated in the clinical teams, so that they can actively participate in the clinical pathway redesign.

#### **What role does technology play in VdH's transition to VBHC? Have there been any major technological changes you had to implement along the way?**

Technology plays a very important role since all the information coming from different actors (patient, caregivers, doctors, etc.) must be collected using digital tools. Furthermore, all this information has to be analysed and displayed in real time and in a simple way to allow actions to be taken. Naturally, it must be integrated with the hospital information system (HIS).

With regard to the VBHC implementation, we internally created a platform to develop:

- a tool to generate and send questionnaires and collect information from patients and/or caregivers
- an algorithm that processes the information and presents it as a diagram considering health areas around the clinical condition
- a balanced scorecard to show all relevant information using KPIs.

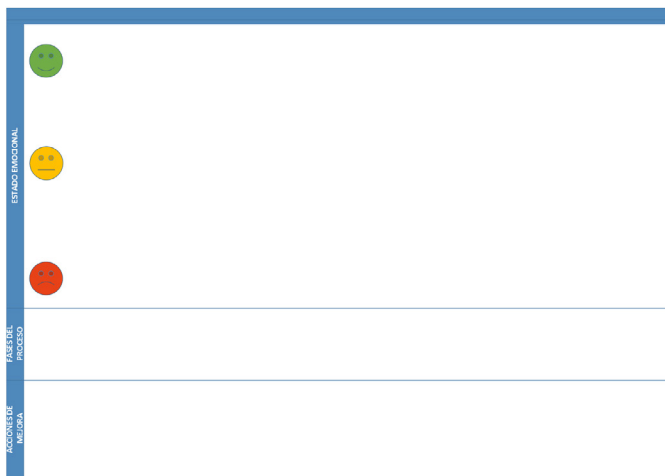
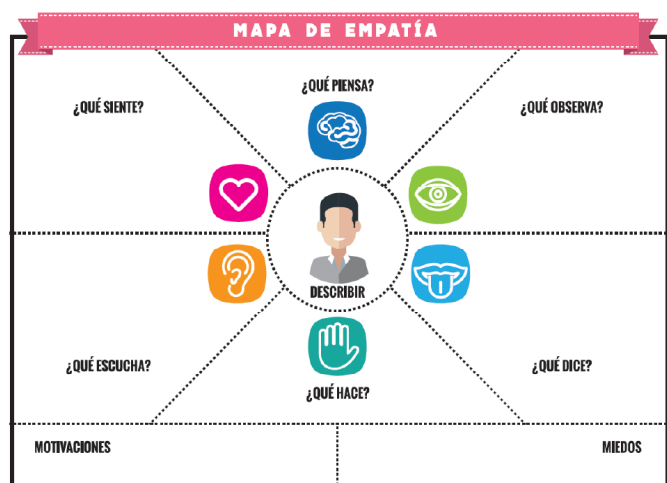


Figure 3. A Session with Haemophilia Patients. There, a Journey Map and an Empathy Map were drawn to collect the patient experience and detect potential changes in the process to add more Value to the patient.

**Please tell us more about how you receive self-reported results from patients and use these in clinical practice.**

Once the data are received and processed on our server and a spider diagram is built on health areas around the disease, clinicians can anticipate the patient’s needs and a personalised care process can be built depending on each patient’s requirements.

One example for this is the objectification of a high depression rate in a group of patients. Before an outpatient clinic visit with the neurologist, these patients are referred to the psychologist/psychiatrist where the patient fill in a motivational questionnaire and the decision on the treatment is taken if necessary.

**Can you give any examples of any prominent misalignments between patients’ expectations and the**

**existing care provision that you discovered? How have you addressed those?**

One such example comes from the stroke patients sessions. For these sessions, we built a Decision Tree to help us choose the patient profiles, so that we could have a variety of experiences within the same clinical condition in the room. For the stroke patient session, there were patients of all sequelae levels.

Specifically, a patient who did not have sequelae after stroke, but whose brother died of stroke, let us know how grateful she was but also how difficult it had been for her after discharge. She was told to quit smoking and was referred to primary care to join a respective programme. The woman was given a treatment, which eventually made her go to the ER as she suspected infarction. At the ER she was sent back to primary care to change her treatment. However, with the second treatment she ended up in the ER





Figure 4. Team of the PED Project Comprised of Staff from Ospedali Riuniti di Ancona, Ospedale Mauriziano di Torino, UZ Gent University Hospital and Hospital Universitari Vall d'Hebron.

again – and so she was going back and forth, but didn't quit smoking in the end.

What was she actually saying? Because of the silos between hospital and primary care and of how the pathways between the two are organised, it is difficult to quit smoking, i.e. to adhere to a treatment.

Out of this session a group of professionals from both primary care (led by neurologist Dr Manuel Milian) and the hospital (led by neurologist Dr Carlos Molina) was formed to work on the discharge process. Currently, this group is working on two main processes. One is a shared discharge follow-up via the Farmalarm platform. The other is an app for those primary care patients who have been identified as being at risk of stroke; the app should facilitate the change in their lifestyle.

#### **Last year, the Paediatric Infectious Diseases and Immunodeficiencies Unit of VdH won the VBHC Dragons Endorsement prize. What are the key take-aways from this achievement?**

The participation in the Paediatric Immunodeficiency Diseases (PID) Early Detection (PED) project has undoubtedly been a key factor for the VBHC implementation. Four hospitals (Ospedali Riuniti di Ancona and Ospedale Mauriziano di Torino in Italy; Hospital Universitari Vall d'Hebron in Spain; and UZ Gent University Hospital in Belgium) have worked together (Figure 4) to create a solid network involving integrated practice units (IPU), to provide patients and relatives with an early diagnosis of PID with standardised diagnostic, therapeutic and follow-up protocols and improve the quality of life for PID patients. The aim of this project is to reduce the PID diagnostic delay, which is about 8.8 years with 50% of people undiagnosed.

The results can currently be appreciated in two aspects.

The first is early diagnosis. Newborn screening for SCID and a pilot phase of the PIDCAP project with around 300,000

individuals are being implemented in Catalonia. The PIDCAP project has made possible the screening of more than 100,000 individuals. Referral rate and quality have significantly improved. Also, a PDTA has already been organised in the Marche region (Italy) with the approval granted by the Health Administration in June 2019, and is ongoing in the Piedmont region. These key figures are part of the pathway design that allows to eliminate a number of unnecessary exams and anticipates the diagnosis of PIDs.

The second one is dissemination. Colleagues from the Ghent University Hospital have set up an interactive website to raise awareness and share information about PID with primary care practitioners and non-PID specialists.

In summary, this combination of efforts constitutes a very powerful initiative that is pivotal for early diagnosis of PID. There's still a long way to go. The PED project has a great potential to deliver superior patient value to patients with rare diseases, from newborns to elderly, decreasing mortality rates, improving patients' quality of life and reducing costs in the whole healthcare cycle.

#### **So far, what have been the most important 'lessons learnt' for VdH on its way to VBHC?**

- Promotion of professional leadership and team work by building trust among the staff (conflict resolution, commitment to each other, assuming responsibilities, defining and obtaining results, identifying value from the patient's perspective).
- Elimination of non-value activities and practices, always from the patient's perspective.
- Change management is not easy, let's be perseverant!
- Let's look for the easiest way to do it. Let's build the Minimum Viable Product and try it. Waiting for it to be complete and perfect raises frustration associated with waiting times.
- Make the problem visible, so that we can solve it.
- At the beginning, we have to go for the quick wins and make them visible to inspire the continuous improvement in our daily work.
- It is necessary to take a chance and step out of our comfort zone to grow.
- Let the team grow at their own pace and let them make mistakes when necessary, so that they are learning by doing.

Implementation of VBHC is an exciting, ambitious long-term project, and we're just at the departure line. Let's keep it going!

#### **Conflict of Interest**

None. ■

*The interview is under the umbrella of Health Services Research Group, Institut de Recerca Vall d'Hebron, Barcelona, Spain.*

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# Early Diagnosis of Cancer at Greater Manchester Rapid Diagnostic Centre

Author: [Barney Schofield](#) | Director of Planning and Delivery | Northern Care Alliance | Manchester | UK

Author: [Roger Prudham](#) | Clinical Director | Northern Care Alliance Rapid Diagnostic Centre | Manchester | UK

The Greater Manchester Rapid Diagnostic Centre Programme offers a new model of cancer care that aims to improve patient outcomes across the Greater Manchester area. The centre offers a new way of rapidly investigating patients with suspected cancer symptoms, so that they can receive appropriate treatment as soon as possible. HealthManagement.org spoke to Barney Schofield, Director of Planning and Delivery, Northern Care Alliance and Roger Prudham, Clinical Director of Northern Care Alliance Rapid Diagnostic Centre to find out more about this initiative and its goals, vision and performance.



## Key Points

- The Greater Manchester Rapid Diagnostic Centre Programme offers rapid investigation of patients with suspected cancer symptoms.
- Northern Care Alliance is the first site in Greater Manchester to develop a Rapid Diagnostic Centre.
- The Centre delivers a model that gets patients into the first diagnostic test within no longer than seven days of referral and diagnosis on the same day, whenever possible.

### ***What is behind the English cancer policy for Rapid Diagnostic Centres? What is it trying to solve or achieve?***

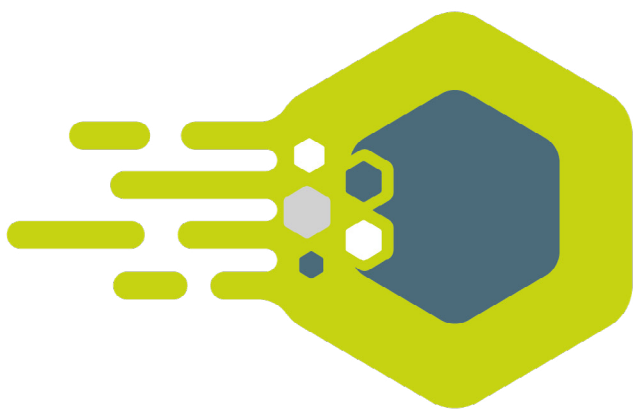
The aims and the intentions of Rapid Diagnostic Centres are framed within the national long-term plan for healthcare in England. Recognised within that plan are the opportunities to make major inroads in both the early diagnosis of cancer and the recognition that too many patients are waiting too long to receive a diagnosis of cancer once they've presented to their general practitioner or elsewhere in the system. The policy aims of rapid diagnostic centres are twofold: one is to speed up the diagnosis of cancer and reduce the anxiety and wait that patients experience to receive that diagnosis; and two, to diagnose cancer at an earlier stage of the disease. This is in line with the overall policy goal for England that by the year 2028, 75% of all cancers should be diagnosed at stage 1 or

stage 2, when they're more treatable and the outcomes for patients are better. In Greater Manchester, as is true in many other parts of England, we're still some distance away from that national goal. Therefore, we have a big opportunity to address late-stage cancer diagnosis and a new way of rapidly investigating patients with suspected cancer.

### ***Greater Manchester Cancer Alliance is testing a new way of rapidly investigating patients with suspected cancer. Can you tell us about this initiative?***

Within the Greater Manchester area, there are pockets of population that are not economically strong, where there are health inequalities and where outcomes are comparatively poorer. The hospital group that we work for serves about one-third of the Greater Manchester population,





# RAPID

## DIAGNOSTIC CENTRES IN GREATER MANCHESTER

and within that population, cancer is a huge burden. We are the first in Greater Manchester to pilot the development of a rapid diagnostic centre and take the initiative forward at an accelerated pace. The aim is to develop and deliver a rapid pathway where general practitioners can refer patients with vague symptoms of cancer into one place. Those symptoms will be investigated rapidly within a pathway where patients have a single point of access and a single point of contact from the point of referral and have support along that journey from clinical nurse specialists and care navigators. It is a novel service model because previously, at the point of referral, primary care physicians had to decide which specialist pathway to refer their patient into - whether it be a lung pathway or an upper GI, lower GI pathway or urology pathway. Sometimes, it's not clear what the underlying cause of the symptoms could be, but symptoms must be investigated. Hence, this is a pathway that's based on symptoms rather than body parts or specialist teams.

### ***What are the goals of these Rapid Diagnostic Centres?***

The goal is to diagnose cancer at an earlier stage. For this, the cohort of people that we've initially targeted includes patients with vague symptoms, which could have any number of different causes. There is plenty of published evidence that these patients wait longer for a diagnosis, longer for treatment and visit their general practitioner more frequently before they're referred onwards. They also have comparatively poorer outcomes compared to patients who have more specific symptoms. Our aim is to deliver a model that gets patients into that first diagnostic test within no longer than seven days of referral from their general practitioner and, where possible, to get the diagnosis on the same day. This is significantly different from what has historically been the model, with diagnostic tests delivered over an extended time span, often requiring multiple visits to healthcare sites and less coordination of that diagnostic journey, as patients and general practitioners try and navigate their way around different hospital departments.

### ***When you say rapid, what does that mean exactly?***

Rapid applies to all patients presenting with cancer symptoms, not just the patients who are currently going through our Rapid Diagnostic Centre model. The vision by 2024 is that all or most patients with suspected cancers will be referred in via a Rapid Diagnostic approach. The national target for cancer diagnosis is that patients should receive a yes or no diagnosis of cancer within 28 days of them being referred by their general practitioners. That's the overall goal. But within the Rapid Diagnostic Centre, we're trying to achieve the same thing within seven days or less. Therefore, the goal is to go further and faster than the overall national goal. It may not be possible to achieve this for all patients, but our aim is to achieve diagnosis in a single visit with the minimum of delay.

### ***Are there any specific types of cancers that are prioritised, or is this rapid diagnosis focused on all types of cancers?***

There is a diverse range of cancers that we're diagnosing through the Rapid Diagnostic Centre. We've currently diagnosed lung cancers, urological cancers, haematological cancers, breast cancers, head and neck cancers, upper GI and lower GI cancers. This goes to show how difficult it is to place these patients into very specific pathways at the point of referral, before they've been through a Rapid Diagnostic Centre, otherwise, they can end up on the wrong pathway being investigated by clinical teams trying to look for a cancer that they don't have.

### ***What type of digital technology is being used by Greater Manchester to improve diagnosis, make it faster and more accurate and to improve patient experience?***

At the moment, we're really only scratching the surface of the long-term digital potential of the Rapid Diagnostic Centre. There is a whole range of enabling and digital technologies, without which the Rapid Diagnostic Centre



couldn't exist. Amongst these is digital radiology, which allows us to access the radiologists that we need to provide a reported scan within two hours of the scan. That is what we're currently piloting within the Centre, and we want to roll that out for many more cancer patients as we go forward. The development of a single system-wide radiology picture and archiving system is critical to the development of Rapid Diagnostic Centres. Alongside that is the development of digital pathology applying the same principles.

***In terms of patient experience, what has been the feedback?***

We can't overstate how much patient experience is central to the policy intent. This is not just about patient outcomes; it's about how patients are supported throughout their diagnosis of cancer. The Rapid Diagnostic Centre model is designed to address and acknowledge deficiencies in the patient pathway and the poor patient experiences as they go through their diagnostic journey. One of the most gratifying things which encourages us that we're doing the right thing is through the patient feedback that we get, and how much people appreciate the lack of delay, the reduced anxiety and how

much people appreciate the personal touch and support they get from the Rapid Diagnostic Centre team. The hand-holding through this journey, the telephone call to discuss their symptoms very quickly after the referral has been received, the prompt care and attention, the coordination, the single point of contact and the personalisation are things that have received the most positive feedback. We can also see that patients appreciate the speed with which the results are delivered after the test has taken place.

***Do you have personalised procedures, or do the patients have to go through a standardised process?***

That is a really good question. It's absolutely not a conveyor belt. One of the most important things that happen within the Rapid Diagnostic Centre is a clinical triage of the referral, backed up by a telephone call, so that we can make sure that we have access to the best intelligence from the patient themselves. Also, referrals arrive in the Rapid Diagnostic Centre with a battery of blood tests already having been requested and carried out. At that point, we would look for any previous scans that the patient has had and their clinical history that we have on our digital information systems. Based on that, we form a view about the right sequence of diagnostic tests to get to the bottom of the presenting symptoms. What we're seeing is, for most patients, the first diagnostic test is a contrast CT scan of the thorax, abdomen and pelvis, but the Centre has access to many other tests as well, including MRI, ultrasound, gastroscopy, colonoscopy and other primary diagnostic tests required to investigate the symptoms.

***What are the main drivers and key performance indicators for this initiative?***

What drives us to do this, notwithstanding the national government policy goals in England, is what we want to do locally for our patients and our population. We're seeing huge increases in demand for our specialist teams to investigate cancer. The current service model, if we weren't to do anything with it, would have difficulties in keeping pace with that level of growing demand. There's got to be a different way of doing things.

We want to transform the patient experience, create a simpler model of diagnosing cancer, reduce delays and make better use of the specialist workforce that we have. Many of the current models rely on medically led service models, whereas within the Rapid Diagnostic Centre, we're maximising the use of specialist nurses and advanced nursing practice and delivering a service model which ought to, over time, demonstrate high levels of value and financial sustainability.

### ***What challenges have you faced when implementing the Rapid Diagnostic Centre?***

There have been huge operational, clinical, financial and logistical hurdles to overcome in the setup phase. One obvious point is that you can't make changes to the way cancer pathways and working cancers are diagnosed until you have absolute confidence in the safety and the effectiveness of the model that you're going to introduce because if that's not right, it will cost lives. It is important to take care of all the details about how patients would flow through the pathway, how the digital underpinning process would work, recruiting the right workforce with the right skills etc. The preparatory work is critical to getting a sense of credibility and confidence from referring clinicians and from secondary care that the Rapid Diagnostic Centre is a safe and viable place to send patients and investigate cancers. Alongside that, we faced the normal kind of logistical hurdles of office space, clinic space, getting access to the right diagnostic test capacity that the Centre relies on, securing the right medical input, etc. One hurdle that we certainly incurred was COVID-19. During the first peak of the pandemic, many of the nursing staff that we recruited to work in the Rapid Diagnostic Centre had critical care skills and were required to work in COVID-19 escalated areas. That delayed the implementation by a number of weeks, but as soon as we were in the post-peak period, we went live with the Rapid Diagnostic Centre pathway. This was a pivotal time, as many patients were nervous about the NHS system and about the prospect of experiencing delays. We implemented the Rapid Diagnostic Centre at the right time in the post-peak COVID-19 period.

### ***Which diagnostic solutions are being used to facilitate the goal of rapid diagnosis?***

Our solutions are designed in conjunction with recommendations from NHS England, the Greater Manchester Cancer Alliance, and other key players within the local health economy. We use a number of concise tests that are available to general practitioners that could give us an indication of where a problem might be before the patient arrives in our clinic. That would include a basic blood count and biochemistry test, thyroid function tests in case an overactive thyroid was a cause of weight loss, serological tests that can be specific to cancer such as CA-199 in case of a carcinogen of the pancreas, CA-125 for carcinoma of the ovary and CEA for bowel cancer. Celiac disease, for example, can cause weight loss and diarrhoea and could give symptoms that mimic cancer. Therefore we use a whole range of tests that would be available quickly and can be undertaken within primary care, so that on the day that we meet a patient, we already have an idea that we've excluded other things that could present as symptoms suggestive but not specific to cancer.

The primary diagnostic modality on which we rely to give both the patient and the primary care practitioner

the assurance that it is unlikely to be cancer is a CT scan of the thorax, abdomen and pelvis. We worked with radiology partners over several months to identify protected capacity that would give reliable access to CT scan and report within a day of the patient presenting to us. Therefore, we have screening blood tests done in primary care available to us when the patient presents. The patient has a pre-booked CT slot, so there's no stress involved with cancellation or delay. We have pre-booked reporting time, so within a day, we have the result for a patient. In short, it's a CT scan that we rely on. We've looked at other imaging modalities, particularly for younger patients, but have yet to reach a solution as to how we might use MRI scans as a way of screening younger patients without needing to use CT. In all of our patients under 45 years, for example, a specific clinical discussion takes place to determine whether it's justified to expose patients to CT scan.

### ***Is your Centre prepared to handle the demand?***

At present, yes. We have the capacity, we're seeing patients very promptly and are getting results back very promptly. The feedback we're getting from our patients is that it's a very high-quality service. However, there is the possibility that as the awareness and the consciousness of what we provide becomes more appreciated across our health economy, the demand will go up and then we will have to keep pace with that demand. We keep a very close eye on the trend in demand and work very closely with our radiology colleagues and providers. Thinking about cancer and indeed other diseases more widely, there is a recognised requirement for a huge expansion of diagnostic capacity across England as a whole and this is true in Greater Manchester. Growing diagnostic capacity and locating much of this away from our busy acute hospitals, in accessible Community Diagnostic Hubs, is very much part of our long-term plan.

### ***Can you tell us something about the operational infrastructure, staff, etc. that make the Rapid Diagnostic Centre efficient?***

Within our service model, our main job is rapid diagnosis. Many other services have a backlog of patients that they need to follow up over a long period of time. They have patients awaiting treatment, and so on. This is a model that specialises in rapid diagnosis, and that's the way that the process and the pathway and the team are set up - to have a well-governed process that gets patients to the point of a yes/no diagnosis of cancer and then referred on to specialist teams for further investigations and treatment.

The fact that we've got such a focused service model allows us to have a number of key performance indicators that are relevant to the job that we're trying to do. We are not impacted by emergency pressures and other demands



in the same way that some of our specialist colleagues are. We work within a set of nationally defined performance indicators that govern access and time. We have to triage the referral on the same day it's received or the next working day. The telephone consultation with the patient to discuss and assess the symptoms happens very rapidly after referral - the target is to get patients into their first diagnostic tests within seven days, and for that test to be reported within two hours being delivered. We have to give patients a diagnosis of or an exclusion of cancer within 28 days of referral. Patients are entitled to start the treatment for cancer in no longer than 62 days from referrals.

We are governed by a set of national indicators but locally, within the Rapid Diagnostic Centre, we have local indicators that enable us to work well inside those national parameters. We can't promise patients with advanced-stage cancer that we're going to make them live longer, but what we can promise is that we can improve the experience in terms of getting a diagnosis, and getting to the bottom of a problem which has been causing a great deal of stress to them and their family members. Our experience so far is that even when we're delivering devastating news of a life-limiting diagnosis, patients are grateful to us for informing them of that rather than people being angry and upset. They're actually relieved. For these cases, it's about delivering a very positive experience in a group of patients who have often been delayed or have perhaps had a poor experience in the past.

The Rapid Diagnostic Centre is a piece in a jigsaw of the ambition to improve population health outcomes for cancer in Greater Manchester through prevention and diagnosis at an earlier stage as well as more rapid diagnosis. However, the Rapid Diagnostic Centres alone are not going to deliver on that wider population goal and will need to work closely alongside effective screening services, for example.

### ***What role has GE Healthcare played, and how has it helped this initiative?***

**We have been partners with GE Healthcare in the early stage of this journey in providing thought leadership alongside our clinical and managerial expertise in the hospital group to generate the idea and the potential in this model.** We live in a world where technology leads, and then applications and ethics follow. Industry partners like GE Healthcare have a responsibility to let us see what is possible technically both in terms of the way that we acquire data and the way that we may use data and share that data. That is where innovation comes in from industry partners in terms of managing patients in a streamlined and rapid way. There is a lot of data within different systems and having the awareness of that and having applications and solutions that can bring all that together to help it make sense is another area where the industry can help. It's the global nature of GE Healthcare and their access to global

insights and experience of international delivery models, which have been really useful for us right at the outset. GE Healthcare is a key partner with the Northern Care Alliance radiology and in many other clinical areas. We have a range of GE Healthcare technology and infrastructure in use across the hospital group.

### ***What are some pros and cons of this solution?***

The pros speak for themselves in terms of the results that we're seeing with respect to diagnosis and the patient experience. As for the cons, we're still only seeing a relatively small proportion of the overall cancer referrals through the Rapid Diagnostic Centre at present. We'd like to grow our impact to maximise the number of patients who can benefit from the pathway.

We're also aware of our reliance on CT scan and the implications of associated radiation exposure as the programme grows. We are also very reliant on the expertise and capability of our radiologists. None of us are without error, but we put a lot of onus on the radiologists to really deliver. We would also like to see more technology that doesn't involve radiation and is less labour-intensive.

### ***So far, what results and changes have been observed with these Rapid Diagnostic Centres? What has worked well, and what could be improved?***

We need to be able to widen the focus of activity that we have so we can benefit more people and we need to be able to reliably predict how we can pace that. We want to take our methodology and apply it to other more traditional tumour groups. Thinking longer term, we can think beyond cancer to other conditions, which can cause as much morbidity and mortality as cancer. We are diagnosing probably 10 to 15% of patients who come through the Centre with non-cancerous, but other serious pathology, which we then refer on, so the benefit of the Rapid Diagnostic Centre is felt in other areas of disease detection and diagnosis. We could think about how we would design a suspected airway disease pathway or a suspected heart failure pathway or a suspected vascular disease pathway, for example. That is still a good few years off, but that is the ambition in the long term. Also, leveraging the benefit of technology is a key part of the vision and understanding the potential of Artificial Intelligence (AI) and decision support tools to provide greater precision and targeted diagnostics. ■



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# The Transformative Power of the Patient Voice

◆ Author: [Fabian Bolin](#) | Keynote speaker | Co-founder of WarOnCancer | Stockholm | Sweden

How to amplify the voice of cancer patients worldwide in order to accelerate comprehensive care and improve the mental health of everyone affected by cancer.



## Key Points

- The active patient is a novelty and the underlying assumption is that the patient will remain passive during their treatment.
- The War On Cancer app is a social cancer support tool for people in and after treatment, and their loved ones.
- The War On Cancer app aims to improve the mental health of those affected by cancer by developing a product that places the wellbeing of its members in focus, always.
- Healthcare has failed to recognise or sufficiently address the mental health effects that cancer creates.
- The healthcare sector will have to transform from a production-oriented approach to a service-oriented type of business, where customer happiness becomes the goal.

## The Origins of Our Understanding of Cancer Patients

For many, the word “patient” conjures up a vision of quiet suffering, of someone lying patiently in a bed waiting for the doctor to come by and execute their expertise. There is an unequal relationship between the user of healthcare services and the provider. The user is described simply as suffering, while the healthcare professional has a title, be it nurse, doctor, physiotherapist, or phlebotomist.

Patient comes from the Latin word “patiens,” from “patior,” meaning to suffer or to bear. The patient, in this language, is truly passive—bearing whatever suffering is necessary and tolerating patiently the interventions of the outside expert.

Therefore, the active patient is an obvious contradiction in terms, and it is this underlying assumption of passivity that becomes most dangerous because the user of healthcare services takes a backseat in treatment and care that drastically impacts their health and wellbeing. The healthcare professional assumes full control and the patient abides, doing what s/he is told, and then patiently waits to recover. The healthcare professional is the healer, while the recipient of healthcare services is the healed who takes little or no part in any decision and cannot actively take part in weighing alternative options. This kind of uninvolved approach on behalf of the patient leads to feeling out of

control of their own health and wellbeing. It’s already proven that a cancer diagnosis affects mental health – feeling out of control and uninvolved in critical decisions exacerbate their mental health and wellbeing.

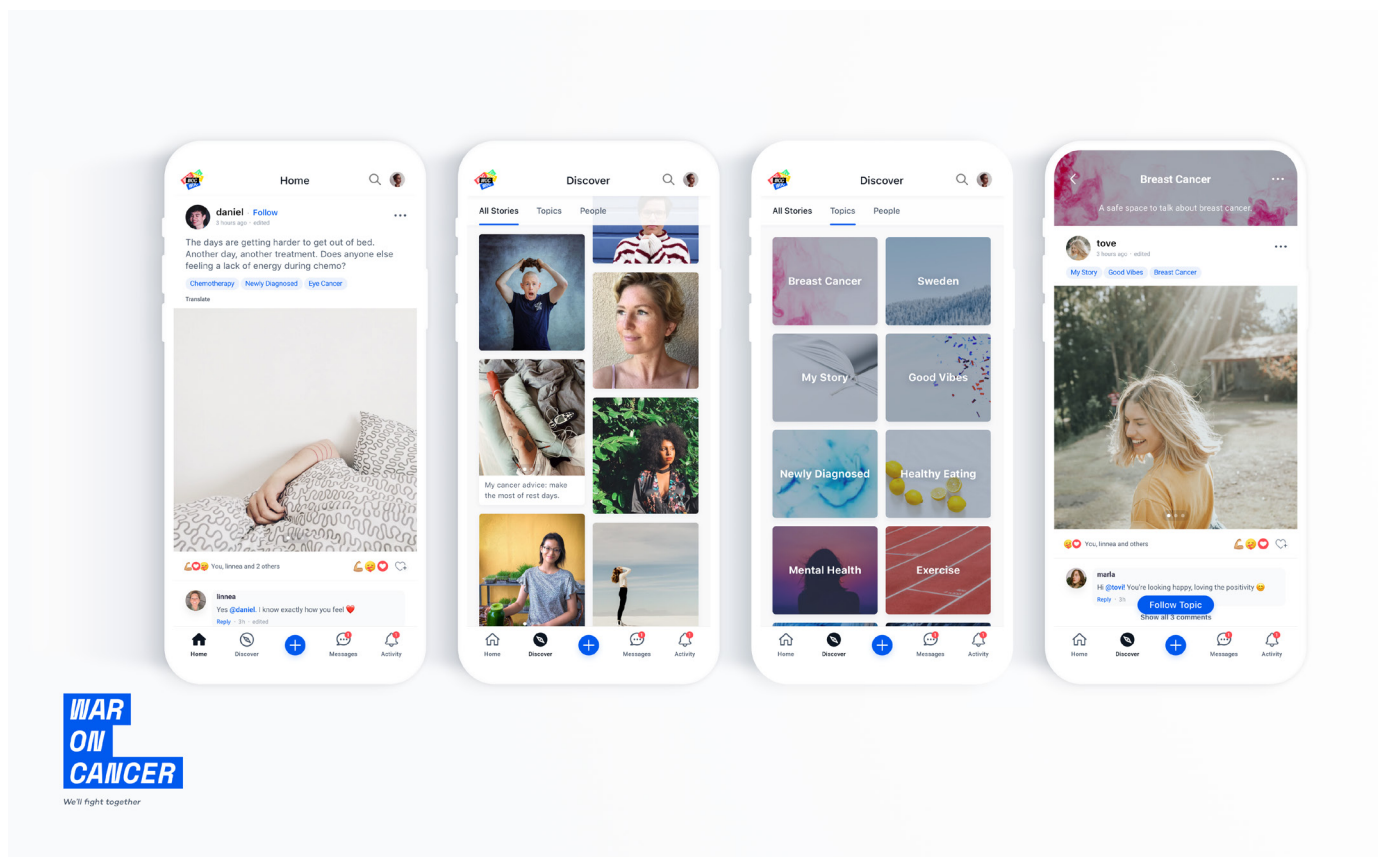
I can’t speak for all patients, but, as someone who has gone through cancer and am currently in remission following more than 900 days of chemotherapy for acute lymphoblastic leukaemia (ALL), an aggressive form of blood cancer, I refuse that this is the best option for patients.

After being diagnosed in 2015, at 28 years of age, I began documenting my cancer battle on a blog, which made me realise the true power of storytelling and how sharing my story helped me cope with my ‘cancer trauma’ and what it meant to be a patient in today’s healthcare system. Sharing my story helped me process what I was going through, emotionally and psychologically, but also gave me a sense of purpose that I had never felt before.

This, together with a strong urge to help others affected by cancer, became the foundation for the [War On Cancer](#) app – a digital support tool and network for people in and after treatment, and their loved ones.

## The Correlation Between Mental Health and Cancer

Before we go into the way in which the War On Cancer app improves the mental health of everyone affected



by cancer, it's important to understand the way in which cancer affects mental health. To start with, each individual's mental health journey during cancer is, on some level, unique and there is no one-size-fits-all description or prescription. However, one experience that everyone affected by cancer can relate to is the experience of loss. Loss of career, or identity, the ability to have kids, financial stability, self-worth, or simply loss of control. Combine loss with periodically extreme levels of stress and you have a dangerous combination which will inevitably take a toll on your mental health.

From consulting research and experts such as psychologists and counsellors within this field, it's clear that cancer can inflict trauma on someone going through cancer, which subsequently can result in either PTSD (post-traumatic stress disorder) and/or clinical depression.

Studies have varied in the assessment of patients for the full syndrome of PTSD (i.e., all DSM criteria met) or only some of the PTSD-related symptoms. Because of this, incidence rates vary accordingly. Yet, research shows that the incidence of the full syndrome of PTSD ranges from 3% to 4% in patients recently diagnosed with early-stage disease to [35% in patients](#) evaluated after treatment. When the incidence of PTSD-like symptoms (not meeting all diagnostic criteria) are measured, rates are higher, ranging from 20% in patients with early-stage cancer to 80% in those with recurrent cancer.

Clinical depression affects approximately [15% to 25%](#) of cancer patients, and is believed to affect men and women with cancer equally. Individuals and families who face a diagnosis of cancer will experience varying levels of stress and emotional upset. Depression in people with cancer doesn't "only" affect the person going through cancer, but also has a major negative impact on their families.

So, depending on the overlap (which is yet to be determined), it's pretty safe to say that most people who experience cancer are in need of mental health support.

### Leveraging Technology to Improve Mental Health and Amplify the Patient's Experience

As a person who's experienced cancer and a patient in the healthcare system, I was made acutely aware of the need for mental health support that isn't currently adequately addressed or fulfilled by healthcare. That was the idea that founded the War On Cancer app, and today, we aim to radically improve the mental health of those affected by cancer by developing a product that places the whole wellbeing of its members in focus, always. The functionality of the app is directly connected to trauma-coping mechanisms such as journaling, connecting with others who can relate, and finding answers to important, day-to-day questions from people who know what it means to go through cancer, and are currently not addressed by



medical staff. What makes War On Cancer unique is that we're not only creating a web of support for everyone affected by cancer, but amplifying their voices through "Health Studies" – a function in the War On Cancer app that allows members to provide insights about their experience with cancer through targeted surveys that contribute directly to cancer research. These insights, such as quality of life assessments or perceived quality of care, have the potential to improve healthcare across the globe and truly leverage the voice of the patient in cancer research.

How do Health Studies improve the wellbeing of members on the War On Cancer app? It turns out, [helping others](#) is an effective coping mechanism for trauma, PTSD and depression. By making it easy to directly contribute to cancer research, War On Cancer members are empowered to leverage their experience to improve the wellbeing of future cancer patients, but are also in control of what studies they wish to partake in. For every study conducted in the app, the member understands 1) which institution is behind the study and 2) the purpose of the study. Through personal storytelling and direct contribution to research all in one place, members of the app are empowered to help others and impact the future of cancer, which helps them feel a larger sense of belonging and purpose during and after their struggle with cancer.

### Healthcare's Narrow Approach to the Well-being of Cancer Patients

The problem healthcare currently faces is the failure to recognise or sufficiently address the mental health effects that cancer creates. Most oncology departments focus solely on the main goal – survival. This is, naturally, top priority, especially since not long ago, cancer was a virtual death sentence and surviving was a miracle. But, thanks to the advancements in cancer research, [two out of three](#) survive cancer today. Tomorrow, it's going to be three out of four, and at some point in a not too distant future, survival will be the norm, though many may have to medicate for the rest of their lives. Cancer will become more of a chronic disease than a deadly one.

What does this mean for the healthcare institutions? Patients, for lack of a better word, will increasingly demand a comprehensive approach to treatment, rather than focusing solely on survival. Their physical and mental needs, which varies from patient to patient, need to be addressed and prioritised. Thus, the healthcare sector must transform their production-oriented approach, where maximum survival is the only measure of success, to a service-oriented type of service, where customer happiness becomes the goal. In the world of healthcare, this means delivering on patients' expectations and perceived quality of care.

### Understanding and Accelerating a More Informed, Healthier Future

In order to achieve this, we need to comprehensively look at the way we perceive healthcare and challenge the role it plays in the larger ecosystem of society.

Firstly, there needs to be a better understanding of, and develop, a definition of health, and determine what hospitals and other healthcare institutions' role is in delivering on the needs and health of its citizens. If we decide to keep the understanding of health focused on only physical health, such as survival and the ability to function, people struck by cancer will continue to struggle with mental health during and after cancer treatment. This will have a major impact on their quality of life, financial situation, family wellbeing, and more. Considering global cancer rates are expected to hit [22 million](#) new cases per year by 2030, if these people's mental health and wellbeing needs are not adequately addressed, this negative impact will shake the very fabric of society at large.

However, if we broaden our definition of health to include the whole person's health, we can significantly improve the mental health and quality of life of everyone affected by cancer. By incorporating support from psychologists, career advisors, personal trainers, spiritual leaders, financial advisors, relationship experts, physiotherapists, and encourage personal growth and self-actualisation into healthcare, we effectively listen to and deliver on the individual needs of those affected by cancer, during and after treatment. This is what many people, to some extent or another, need, and, it's clear that in most cases, hospitals are not currently equipped to provide this kind of comprehensive care.

Adopting this whole-being approach to health demands a shift in mindset from measuring success only by means of survival and physical needs, to guiding the patient through their entire health journey, customised around the individual. One of the biggest challenges to assessing patient needs is the lack of digitisation within the healthcare sector, as well as information overload. Physicians today are stretched to their limits in regards to administration, data processing, and research development. Currently, it is a real challenge for physicians to process and deliver on the multifaceted needs and insights of patients. Leveraging technology to change the way in which healthcare tackles the quality of life of cancer patients is essential to accelerate and effectivise a comprehensive approach to the health and wellbeing of those affected by cancer.

We also need to take a good, hard look at Patient Reported Outcome Measures (PROMs). Research suggests that collecting PROMs lead to better care delivery and increased mental health for patients. To accelerate the adoption process, we should implement a

system where PROM data is used to compare and reward hospital performance. This would be an effective driver in improving patient satisfaction, an obvious goal for healthcare, now and in the future.

This is where the War On Cancer app comes in. Our aim with War On Cancer is to amplify the voice of patients and collaborate with healthcare institutions to better understand and address patient needs. By leveraging technology, War On Cancer is building a platform where people can connect and share their experience with cancer, and at the same time make it easy for them to contribute to cancer research and improve healthcare through in-app surveys. On the flip side of that coin, we help researchers access and connect with thousands of real-world patients all in one place, in order to draw more informed conclusions and transform care to become more individualised and patient-centric. By building that bridge, we hope to connect and contribute critical data and accelerate the understanding of what needs to be

done to improve the overall quality of life of patients during and after cancer treatment.

In the same way that there is no single pill that can cure every disease, there is not one doctor, one hospital, one pharmaceutical company, or one research team that can deliver perfect, comprehensive care to every person going through cancer, to help them achieve a higher quality of life. This is only possible by boosting collaborating between all stakeholders, and we at War On Cancer are ready to do so.

By combining real-world patient big data insights and incorporating them in order to bring about a more comprehensive approach to the healthcare ecosystem, it is possible to transform the world for the better for everyone affected by cancer.

#### Conflict of Interest

None. ■



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# Patients' Revolution Patients' Evolution

◆ Author: [Dr Begoña San Jose](#) | Founder | Beandgo | Vienna | Austria

Healthcare is in constant change. Today the change is driven by the patients. Access to patient data has changed the way healthcare is delivered, where it is delivered and who delivers it. A lot has already been achieved, and although there is still long way to go, the result will be the truly person-centric healthcare.



## Key Points

- Access to real-world data and patient-reported outcomes presents the power and the potential to redesign healthcare.
- Patients have an increasingly active role in their health, and they also expect healthcare to deliver on outcomes that matter to them.
- Healthcare will continue to be data-driven, but patients are more than their data. Understanding them and their needs would enable patient centricity and a move away from a one-size-fits-all system.
- Although the healthcare transformation towards data-driven and patient-centric has been fast with regard to some diseases, it is lagging behind in some others, such as mental health, which remains disease-focussed, physician-centric, poor in data and with little patient involvement.

## Historical Overview of Patient's Role

Healthcare is in constant change, and currently we are going through the patients' revolution. Patients have been the passive receivers of healthcare services for many years. Just a few decades ago, the most common were communicable diseases. Attitudes towards health – and lack of it – were long thought to be determined by some supernatural power, or god, leading to the belief that the restoration of health also depended on some supernatural sources and had little or nothing to do with one's own behaviour. That was precisely the role of the gods, like Asklepios in ancient Greece, or of a doctor in the more recent past. The relationship was unidirectional and characterised by what we would call today information asymmetry.

In recent years, with the change in the epidemiological profile of the population and the emergence of chronic conditions, the role of patients has started changing progressively. Epidemiological studies highlighted the importance of lifestyle at the onset and in the progression of diseases, and therefore, the role of the patients' behaviour became more and more relevant. Cigarette smoking was recognised as the cause at the time of the new lung cancer epidemic. In the 1950s, the first studies

were performed comparing the risks for smokers and non-smokers and the evidence about the relationship was clear. Patient behaviour, in this case smoking, was associated with an increased risk of cancer. Other cases followed. The investigations and clinical practice were led by a number of cross-sectional epidemiological studies that showed the differential risk between smokers and non-smokers. These were supported by longitudinal studies, which were able to show not only an association but also the causality of the relationship. Clinical practice began to follow scientific evidence with [The Cochrane Collaboration](#) leading the way.

Obesity, sedentarism and exposure to stressors were also examined in relation to several chronic conditions, such as diabetes, cardiovascular disease and others. My own PhD thesis, published 20 years ago, studied the relationship between alcohol consumption and several health outcomes. Studies like this became sophisticated and looked at characteristics beyond a 0-1 model – smoking and not smoking, drinking and not drinking. They aimed to disentangle the relationships and to understand other aspects of the unhealthy behavioural pattern, such as social circumstances, the amount and the frequency, and to determine the thresholds and better understand the biological and psychological mechanisms explaining

such correlations. Those studies were often the result of robust epidemiological research, much of which was based on self-reported population data collected longitudinally. Thousands of people were systematically monitored for many years, and their disease profiles were then collected and compared. [The Framingham Heart Study](#) is nowadays considered one of the longest and most important epidemiological studies in medical history. In the 1960s, this study demonstrated the role of cigarette smoking in the development of heart disease. The evidence resulting from such studies was, however, conclusive when the results were clear, although the methodological limitations were largely discussed in a dedicated section, which included the extrapolation of patient self-reported data to the actual consumption.

In any case, these studies represented a milestone in the history of medicine, and in the way medicine would be practiced. Patients were no longer passive receivers of medical treatments; they were held responsible for both the onset and the progression of their own diseases. In parallel to the traditional medical approaches, which included pharmacological treatment or surgical interventions, lifestyle changes were then suggested as part of the interventions, in some instances being as or even more effective as the latter.

### Role of Technology

Electronic Health Records (EHR) represented a breakthrough in the field, and through these systems access to systematic data from patients' encounters with healthcare providers was granted. Soon, and as data became valuable, quality of captured data improved and systematic analyses were made easy and accessible. However, these still had considerable limitations, especially because Electronic Health Records, while being good at registering changes in weight, body mass index or smoking habits, remained disconnected from patients' everyday lives. The issue was again, technically speaking, easy to solve with the introduction of connected devices and the Internet of Things in the medical field, which gave the possibility to have even more data points regarding patient behaviour outside medical offices.

Nowadays, for example, it is not only already incorporated in the clinical guidelines but is also public knowledge that walking 10,000 steps a day is associated with a reduction in cardiovascular risk compared to more sedentary lifestyles. To add to this 'data collection fever', medical devices are able to monitor our sugar levels not only when we take measurements, but also through connected devices allowing for continuous glucose monitoring. Therefore, the ability to adjust the clinical guidelines and recommendations is much finer than it was when data were scarce. Patient-reported outcomes and real-world data have emerged as relevant indicators to



measure, monitor and, of course, manage patient health.

### Future Priorities

This data-driven healthcare is at the core of the patient revolution, and technology has certainly enabled this revolution, as is elaborated in this article. There is, however, a long way until we translate this knowledge into better outcomes for patients and much-needed efficiency gains in the healthcare system and at the societal level. Successful applications and sustained healthy lifestyle changes have been studied and led to important advances in the patient activation movement, for example, aiming at describing the patients' stages, connection and commitment in their healthcare journey.

It seems clear that healthcare will continue to be data-driven. However, patient centricity should be at the core of this data-driven movement. Progress is needed in the following areas:

**1) Patients are more than numbers.** Patients' psychological and emotional aspects are core to their well-being, together with their physical health or their more or less objective data. Health, according to the definition used by the World Health Organization since its foundation in 1948, which is still valid and relevant today, is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. It is not just physical; the emotional and psychological aspects are certainly important when translating data and numbers



into actionable and sustainable lifestyle changes directed at the primary or secondary prevention of chronic health conditions.

The first important hurdle is how to translate this knowledge about patients' behaviour negatively affecting their health into sustainable behavioural changes that support healthier outcomes. It is certainly good to know that 10,000 steps reduce cardiovascular risk, but how do we engage with patients to achieve these? How do we engage with patients to reduce and maintain their body mass index within the limits? How do we engage with patients to adopt and sustain healthy lifestyles? Behavioural economics is the field that studies the effects of psychological, cognitive, emotional, cultural and social factors on the decisions of individuals, and in recent years it has been applied to health-related behaviour. Advances

data. Machine learning and artificial intelligence supporting medical decisions is starting to gain a place in healthcare, although, returning to the first point, patient-centricity, or rather human-centricity should prevail beyond the numbers.

**3)** Patients should also have the confidence of the secure, proper and respectful use of their data. **Data protection and data security should be granted and should be top on the agenda**, and not a side issue in this data-driven and patient-centric healthcare. The detailed review of this topic goes beyond the scope of this article but should be seriously considered when moving forward.

Although this transformation has already begun and has made rapid progress for many of the chronic conditions (diabetes and cardiovascular diseases leading the list), it is lagging behind some others, such as mental health, where there is still stigma, dichotomy in the healthcare continuum,

## Any professional supporting people – not just patients – staying healthy is de facto a healthcare provider

in this field are expected to improve patients outcomes as well as compliance and adherence not only to medications but also to lifestyle changes.

**2)** The patient revolution is led by patients who believe that a one-size-fits-all approach to healthcare does not match their needs and that there is room for improvement in patient outcomes and in the much-needed efficiencies in the healthcare system. **This revolution has, however, a domino effect and requires adaptation of the healthcare delivery system as a consequence.** Healthcare is not only provided by traditional healthcare professionals working in hospitals or other healthcare facilities, such as doctors, nurses, physiotherapists. It also includes any other professional who supports people (not only patients) protecting their health, e.g. clinical nutritionists, health coaches, health psychologists, or personal trainers. This certainly creates both challenges and opportunities as healthcare becomes an integral part of living and not a disconnected exercise of encounters with the healthcare system. The first question is the recognition of these professionals as 'healthcare providers', and reimbursement of their services as a consequence. This is, of course, easier to achieve in an outcome-based or value-based system than with a fee-for-service model. Physicians' role has especially changed. They were once in control of most of the medical knowledge – with the above-mentioned information asymmetry – but now are called to integrate and make sense of many diverse and often unstructured

information asymmetry, access difficulties and lack of data. Psychiatrists remain at the centre of the mental health care delivery, and information asymmetry is especially relevant in mental health care. Other mental health professionals, namely psychologists, supporting an increasing number of people coping with anxiety and depression among others, are those acting in primary and secondary prevention and supporting many with physical health challenges and with lifestyle changes. Mental health care delivery remains largely disconnected from the patients' lives. Data regarding mental health are scarce and scattered, and the equivalent of a continuous glucose monitoring device is not available (and may never be). Mental health professionals are still among the late adopters of technologies including electronic health records systems. This, as always, is a challenge but also an opportunity to improve.

**The patients' revolution is here to stay and to bring much-needed improvements in patient outcomes and efficiencies in the healthcare system. Data and technology continue to enable this transformation and need to remain patient-centric to support the patients' evolution.**

### Conflict of Interest

None. ■

# Consumerism in Healthcare – Current Status, Benefits and Challenges

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The COVID-19 pandemic has pushed healthcare to move towards consumerism. This change is being driven by patients who are quickly turning into consumers. Where will this trend lead? Is it time for hospitals and consumers to work together to utilise digital technology in healthcare and to improve healthcare access across all groups of society? How can healthcare embrace consumerism?



## Key Points

- Healthcare is fast becoming consumerised, with the ongoing COVID-19 pandemic fuelling the fire.
- This trend of consumerism is being driven by patients. They will decide who will have access to their personal data. This would be mainly driven by brand trust and perceived value.
- New communication channels, especially digital ones, need to be created to maintain two-way conversations. Communities will play a significant role.
- Consumer-centred healthcare is heavily reliant on digital technology.
- Telehealth is breaking down the geographical proximity advantage and opening the field for increased competition with virtual competitors.
- With easy access to self-monitoring tools, patients are now demanding healthcare services that can leverage these tools and help them in managing their health.
- Marketing needs for healthcare providers must be redefined, adjusting strategy to this emerging target segment that has different needs and is looking for completely different solutions.

The idea of consumerism really took off in the early twentieth century when it was the need of the hour for the survival of businesses. Since then, the wagon of consumerism has never stopped. We live in times when even healthcare is fast becoming “consumerised.” The ongoing COVID-19 crisis has only fuelled this fire.

Consumerism in healthcare is not merely about supporting hospitals, insurance companies and other businesses. Instead, it is being driven by patients, who are increasingly turning into consumers. Furthermore, consumer-centred healthcare is becoming heavily reliant on digital technology. This rings especially true when we look at how the COVID-19 pandemic has transformed healthcare.

To put this into perspective, let us look at a statistic. Over 73% of the users employing digital healthcare tools, such as

artificial intelligence (AI) chatbots and telehealth, to monitor their health in the COVID-19 era are first-timers. The stage is set for a radical change in the way healthcare services will be consumed in the future, in Europe and elsewhere.

### Adoption of Telehealth is Fuelling Consumerism

Significant changes in the healthcare landscape are already conspicuous. Many healthcare systems around the world have embraced telehealth to ensure social distancing. Regions like China, the U.S. and Europe are experiencing an unprecedented surge in the number of consumers demanding virtual healthcare. To keep up with this demand, several digital healthcare platforms are being offered in European nations. The increasing acceptance of telehealth is keeping both doctors and patients safe and setting

Europe on a fruitful path. At the same time, telehealth is breaking down the traditional “geographical proximity” advantage for some healthcare providers and opening the field for increased competition with virtual competitors. All these changes are fuelling consumerism in healthcare.

### Self-Monitoring and Consumer Awareness

Self-monitoring, another catalyst in the transformation of healthcare, is not as difficult as it was once touted to be. More and more people are buying self-monitoring medical devices online. Pulse oximeters, devices that few had even heard of before the past couple of months, are now being sold at unusual rates. With these tiny hand-held devices, people can measure their oxygen saturation levels at home. Self-monitoring and online reporting are not limited to COVID-19. They can easily encompass a host of other health conditions, including many chronic diseases such as diabetes, hypertension, many types of lung diseases etc. With these self-monitoring tools in hand, patients are now demanding healthcare services that can leverage these tools and help them in managing their health.

should be a happy balance between overtreatment and limited accessibility to medical facilities, two problems on the opposite extremes of a spectrum. Undoubtedly, now is the time for hospitals and patients to realise the power consumerism has to revolutionise healthcare, both during and after the COVID-19 crisis.

These are four things hospitals and healthcare providers can consider doing:

- **Focus on experience management:** This is an aspect of consumerism that can simply not be ignored is the consumer experience. In the context of healthcare, this equates to patient experience, which could prove to be a major distinguishing factor between different healthcare providers. Thus, healthcare providers must start thinking about providing personalised care to their patients.
- **Engage consumers through digital channels:** More consumers are now making their decisions without help from third parties. Hence, the benefits they get from subscribing to one healthcare provider over others must be clearly communicated. Hospitals should think about creating patient portals and mobile apps so that their

## As consumerism takes its roots in healthcare, a more symbiotic consumer-provider relationship is on its way in Europe and around the world

### What Will Consumeristic Healthcare Look Like?

With telehealth and self-monitoring being popularised among more and more people, consumeristic healthcare post-COVID-19 is going to be influenced heavily by digital technology. It is going to involve the use of machine-learning algorithms and AI to predict prognoses, smartly distribute work to doctors and nurses and manage patient intake virtually.

Virtual consultations by doctors and clinicians are going to add to the patient experience immensely. It certainly addresses one of the major issues that patients find in their healthcare experience: lack of sufficient interaction with their primary healthcare providers. Digital modes of healthcare dissemination also allow for continuous contact with the patients through simple text messages or video clips – communication mediums that do not necessitate direct interaction but can still improve the patient experience.

### How to Avail the Benefits of Consumerism

As consumerism takes its roots in healthcare, a more symbiotic consumer-provider relationship is on its way in Europe and around the world. Consumerism in healthcare

services become more accessible to patients. Moreover, hospitals and other providers need to innovate their services and outreach based on consumer feedback.

• **Act on increasing price sensitivity:** Pricing is yet another aspect that healthcare providers should reform. Adjusting service prices according to consumer preferences and suggesting alternative cost-effective medicine prescriptions will help foster consumer loyalty and increase patient satisfaction.

• **Leverage partnerships within healthcare ecosystems:** European hospitals should also be prepared for some fundamental changes in their decision-making infrastructure, such as an increase in public-private partnerships (PPPs). Since the expectations of patients from both public and private healthcare providers are the same, PPPs can provide a more consolidated approach to respond to increasing consumerism in the sector.

• **Redesign of marketing channels, strategies, topics and brand positioning:** In addition to providing advanced solutions, services and innovation, the value proposition should be adapted to consumers rather than patients. Preventive medicine gravitates around very different topics

than sick care-oriented medicine. New channels such as social media and digital tools will play a significant role that healthcare providers would need to adapt to. Understanding the needs of consumers that are not necessarily having a health problem will be the pivotal point to build this new 360° marketing and consumer engagement strategies. The new scenario will include providing the solutions that consumers demand in the channels where they are having conversations with brands from other industries (e.g. Facebook, LinkedIn, etc.) and communicating on topics of health-related with brand engagement and lifestyle rather than traditional sick care.

Patients would need to embrace a paradigm shift as well to benefit from this trend. This would include:

- **Willingness to share data:** Patients must be more willing to share their medical data for the benefit of research. The availability of more data can help alter digital healthcare to better suit patient needs and expectations. Feedback is similarly very important so that future services can be better. The main drivers to encourage consumers to share data will be the trust that healthcare brands can create by using tailored marketing actions and also providing immediate value to the consumers in return for data sharing.

- **Embrace “lifestyle medicine”:** Consumerism is an opportunity for patients to get actively involved in their own care. As noted by [Bertalan Meskó](#), “Lifestyle medicine emphasises nutrition, exercise, sleep restoration, stress release, avoidance of toxic substances, mental health and social connectedness as tools to better

health based on scientific evidence. Patients are actively involved in their care. Medication (if needed) and behaviour changes are combined”. Digital tools and wearables play an important role in enabling monitoring and diagnosis in this approach.

### Overcoming the Challenges of Consumerism Creating an All-Inclusive Approach

A major point of contention in the ‘patient’ vs ‘consumer’ debate is whether all strata of the society are, in fact, ready to be consumers. Those facing financial challenges may be discouraged from availing adequate and good-quality healthcare facilities if the industry becomes entirely consumeristic. Similarly, the older population may not be up to date with the latest technologies. This is an important challenge given that this segment of the population provides a significantly large number of consumers.

The COVID-19 crisis is helping healthcare overcome the challenges mentioned above. This is evident from the feedback shared by doctors based on their experiences during the pandemic. Some of the more recent debates and discussions in the area suggest that even those who are limited by financial resources or knowledge of digital technology can avail new-age healthcare during and after the COVID-19 crisis. What this requires is the proper dissemination of information about how to use digital healthcare resources. Hospitals and consumers must work together to know how best to customise digital technology to different groups of people so they are all able to access healthcare. ■

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# Finding Credible Healthcare Information

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Trustworthy health information is a cornerstone of patient/citizen participation in care delivery. Moreover, as the current pandemic shows, it is key to protecting both personal and collective health. The Patient Information Forum strives for both improving the quality of available health information and eliminating the health- and digital-literacy gap.



## Key Points

- Access to high-quality health information is an essential element of individual and public health, especially amid the COVID-19 pandemic.
- The PIF TICK scheme provides a framework for health information producers to ensure reliability of their messages.
- There has been some progress in the recent years in how the health- and digital-literacy gaps are addressed by health organisations, but more work is needed.
- PIF has created a list of recommendations on improving health and digital literacy across the UK.

Supporting and driving up quality and trust in health information has always been at the heart of the Patient Information Forum (PIF) and it has never been more important to signpost the public to trustworthy health information than in the current crisis. We would like to believe that today's patient is armed and fully informed to engage in their care delivery. But is this really the case?

Unfortunately, the current COVID-19 pandemic suggests otherwise and serves to reinforce some of the existing shortcomings in the system, which must be addressed if we are to increase people's ability to stay healthy and manage illnesses effectively, giving them a better quality of life.

Until now, many may have regarded the need for high-quality healthcare information solely as an intervention to guide and support people through an illness, surgery or living with a long-term condition, but the current pandemic has highlighted how vital it is for everyone to have access to accurate, evidence-based, up-to-date and culturally appropriate information to safeguard our personal and collective health.

The COVID-19 crisis has shown how easy it is for unreliable and untrustworthy information to make it into mainstream through social media. We need to address how we help patients and the public to find high-quality health information they can trust. We need to ensure people have confidence in the health information they find on the internet or in community settings.

In July 2020, a survey by PIF of over 800 people found that one in three had delayed accessing care, 75% of these because of COVID-19 concerns (PIF 2020a). Despite the

easing of restrictions, more than half (57%) of all respondents were concerned about attending future appointments. Just under half of respondents had been shielding.

Fear of catching and becoming seriously ill with COVID-19 outweighed concerns about existing health conditions. A lack of trustworthy information and conflicting guidance emerged as the key concerns and barriers to seeking appropriate medical help, even greater than age, gender or an underlying health condition.

Respondents expressed a clear desire to know where they would be seen, whether they would be seen face to face, how they would access facilities upon arrival, what doctors and nurses would be wearing, whether or not they themselves would be wearing a face mask and how they would be kept safe from the threat of the virus.

Patients who are avoiding medical appointments and preventative care out of fear of contracting COVID-19 could be putting themselves at risk of developing a serious illness.

Providing people with clear information about the measures being put in place to protect them will allow them to weigh the risks and benefits of addressing their health needs versus the risk of contracting the virus.

## Lack of Trust and Need for Inclusion

The COVID-19 crisis has highlighted the need for people to have the confidence and trust in the information being provided and the importance of health and digital literacy in ensuring information is inclusive.

To help address these issues and to provide a solution,

PIF has been working with colleagues across the voluntary, public and private sectors to create a quality standard, the PIF TICK.

Consumer research by PIF found 80% of the public would look for a quality mark for health information they could trust. Evidence, plain English and trained staff were the top three criteria for quality health information identified by the public, although all criteria were supported.

But COVID-19 has particularly highlighted the importance of clear messaging, which is culturally appropriate and speaks directly to everyone to help mitigate fears and reduce anxiety. The use of culturally specific imagery and content using voices of communities with lived experience is needed to shape future public messaging. These issues are addressed in the recent Public Health England's (PHE) report *Understanding the impact of COVID-19 on BAME communities* (PHE 2020) and their recommendations apply both to COVID-19 and information on non-communicable diseases associated with inequality, including diabetes, heart disease and obesity. Work already taking place includes an ethnic minority influencer programme and key messages being translated into local community languages but more action is needed including a more streamlined approach nationally and locally to improve translation (Race Disparity Unit 2020).

Ensuring information is inclusive and does not reinforce health inequalities is essential. Involving the community and users in the development and creation of the content, communications and marketing will increase the reach, strengthen the impact of the messages, and so help improve overall health.

These elements are all a key part of the process for producing quality health information and achieving the PIF TICK, a sign for the public that they can trust what they are reading. PIF has produced guidance on all aspects, including user engagement, but we too are committed to continuous improvement and we will undertake a review of our own guidance to make sure it is fit for purpose.

Forty six organisations have joined the PIF TICK scheme since it opened in April 2020 and are in the process of certification. We would encourage as many of you as possible to take a look at the scheme and join us in getting one step closer to giving patients and the public confidence to make the necessary changes and improvements to their health based on trusted information.

The PIF TICK logo can be applied to leaflets, websites, apps and videos or any form of health information that has gone through an organisation's certified production process. To be awarded the PIF TICK an organisation must undergo an assessment to show its production process meets ten criteria addressing issues of accessibility, reliability and user engagement.

The ten criteria for trustworthy health information are:

1. Information is created using a consistent and documented process
2. Staff are trained and supported to produce high-quality information
3. Information meets an identified consumer need
4. Information is based on reliable, up-to-date evidence
5. Patients are involved in the development of health information
6. Information is written in plain English
7. Print and digital information is easy to use and navigate
8. Users can give feedback on information
9. Information is promoted to make sure it reaches those who need it
10. The impact of information is measured.

### Charter to Tackle Inequality

The COVID-19 pandemic has exposed existing health inequalities, hitting disadvantaged communities hardest, and emphasised the link between low health literacy, digital literacy and health inequality.

PIF is calling for all health information providers to sign up to a health and digital literacy [commitment charter](#).

The call to sign the charter comes following the recent publication of PIF's Health and Digital Literacy Survey results, which found that the gap between skills and the complexity of health information is leaving millions excluded from making informed decisions about their health (PIF 2020b).

By signing the charter, organisations are recognising the importance of health and digital literacy and committing to becoming 'health literacy friendly'. In the first month, more than 30 organisations made this important public commitment.

Jonathan Berry, National Lead for Health Literacy at NHS England and Improvement, stated: "Health literacy has a high impact on people's health. It can affect, among other things, how they access and use services, manage a long-term condition, take medication and live healthily. It is also inextricably linked with health inequalities."

Progress has been made since PIF last conducted the survey in 2013 (PIF 2013) with 60% of organisations providing information for those with low literacy or numeracy, compared to 35% in 2013, and 58% are providing information for BAME groups, compared to 39% in 2013.

However, there is more work to be done with only 13% of respondents saying their organisation had a health literacy strategy in place. This represented little progress from 10% in 2013.

The 2019 survey (PIF 2020b) also asked how health information providers were tackling digital literacy, timely as just months later COVID-19 would accelerate the digital ambition of the NHS Long Term Plan. Only 50% of survey respondents had considered equalities impact when introducing digital services.

In the four weeks to 12 April 2020, 71% of routine GP consultations in the UK were delivered remotely, according to the Office for National Statistics (Walker 2020).

However, nine million people lack digital skills, 8% are not connected and 66% with online access do not use the internet or digital tools to support their health.

To help stop this 'digital divide' increasing health inequalities further, PIF is recommending all organisations consider the equalities impact when introducing digital services.

Throughout the survey, a lack of recognition of the importance of health and digital literacy at an organisational level emerged as a key concern (PIF 2020b):

- The biggest perceived barrier to producing health information to address low health literacy was limited understanding of how to develop resources or services (73%).
- The number of respondents saying information producers do not realise the importance of health literacy rose from 53% in 2013 to 60% in 2019.

If we are serious about tackling the health inequalities revealed by the COVID-19 pandemic, then it is important for all organisations producing health information to become health- and digital-literacy friendly. Health information must be clear, consistent and accessible in all its formats if people are to make informed decisions about their health. Ensuring information is inclusive, culturally appropriate and co-produced are all key elements in making content health-literacy friendly.

### Health and Digital Literacy Recommendations

PIF, in partnership with an expert panel, has published the following recommendations to improve health and digital literacy across the UK:

- 1. U.K. National Health strategies:** Incorporate health and digital literacy into health strategies of the four nations of the UK as a key enabler of shared decision-making, supported self-care and self-management and reducing health inequality.
- 2. Organisations producing health information:** Should aspire to become 'health-literacy friendly'.
- 3. NICE:** Develop guidelines on health and digital literacy to drive change and provide an evidence base. Ensure health and digital literacy is recognised in new and updated guidelines, with reference to shared decision-making.

**4. Shared Decision-Making:** Require the provision of 'health-literacy friendly' patient information (that conforms to standards) in planned national standards and guidelines on shared decision-making.

**5. PIF TICK:** Develop specified UK standards on health literacy within the PIF TICK criteria.

**6. Good Practice Guidance:** PIF to develop guide on How to Produce Health Literate Patient Information and promote existing resources, knowledge and tools on health and digital literacy. Develop a health-literacy checklist for information producers.

**7. NHS repository for translated information:** Create a central NHS repository for health literate information in English and other commonly spoken languages, to reduce health inequality in BAME groups exposed by COVID-19. Make NHS App and other national projects available in commonly spoken languages.

**8. Digital Health Literacy:** Raise awareness of the WHO definition of digital health literacy and the personal skills required.

**9. Community skills improvement:** Support motivation and skills improvement through a partnership promoting and signposting health literate information in all formats to public libraries, schools, prisons, pharmacies and other community-based support.

**10. Equalities impact of digital tools:** All organisations should implement the Accessible Information Standard and consider other reasons for digital exclusion/equalities impact including access, skills, motivation when developing digital projects.

The expert panel which advised on recommendations included members from a number of organisations, e.g. PIF, NHSE, Health Education England, etc. ([full list](#)).

### Conflict of Interest

For the Covid Choices survey, PIF received partial financial support from Norgine Ltd, an existing partner organisation. Hill and Knowlton provided pro bono support for quantitative data analysis of the survey. For the Health and Digital Literacy survey, PIF partner TextHelp provided pro bono support to design an accessible PDF of the survey report. ■

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# VBHC in Netherlands:

## What problems could be solved? A report of interviews with 21 Dutch VBHC experts

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Value-based healthcare (VBHC), aimed at improving patient outcomes without increasing costs, is becoming more and more important, as healthcare utilisation and costs continue to rise well above the cost of living. Many initiatives are now being taken to put value-driven care into practice, including in the Netherlands. The question, what problems could actually be solved by applying VBHC, has led to a series of interviews with Dutch VBHC experts. In this paper their insights and opinions are presented and discussed with the aim to provide caregivers, patient advocates, innovators and policymakers with an insight into the existing problems.



### Key Points

- There is insufficient knowledge among healthcare providers about *what* and *who* is of value to the patient.
- There is an unfavourable economic business model.
- Healthcare is primarily organised from the perspective of the doctor and the care institution, not from the patient's perspective.
- The motivation and mutual trust of care workers are under pressure.
- There is little national cohesion in the collection of data and in the analysis of patient groups.
- Parties in healthcare are not specifically focussed on improving health outcomes that truly matter to the patients.

### Introduction

As healthcare utilisation and costs continue to rise well above the cost of living, value-based healthcare has become an increasingly important concept (Porter and Lee 2015). The Value-Based HealthCare model (VBHC) aims to improve patient outcomes without increasing costs (see Appendix). The starting point is to achieve predetermined health values for and with patients, to be discussed with the patients in the doctor's office and among care professionals. Outcomes that are relevant to the patients are determined in a value ratio and measured in a structured way together with costs (Porter 2010). It encourages acceptance in healthcare practices to optimise the relationship between health gained and costs incurred. Many initiatives are now being taken

to put value-driven care into practice, and it will inevitably lead to more research into how resources are deployed and spent (Brady et al. 2020). This concept is also catching on in the Netherlands. The nationwide programme Outcome-Based Healthcare, and the Dutch [Linnean initiative](#), to which hundreds of people have now joined, try to further accelerate the transition to the VBHC system. But is it actually clear which problems can be solved with VBHC? Dutch VBHC experts give their insights and opinions on this in this paper.

### Research Question

We have focussed on the question 'What are the problems in healthcare that can be eliminated by implementing the VBHC concept in practice?' With the answer to this



question, we aim to provide healthcare providers, innovators and policymakers who would like to start or have started a VBHC initiative, with an insight into the possible underlying problems, so that it can serve as a reference in their initiatives. But we also want to inform those who have not (yet) come into contact with VBHC with the answers to this question.

## Methods

To identify the underlying problems, a series of semi-structured interviews were held in 2019 with 21 Dutch experts who are intensively involved in VBHC initiatives. The interviewees were approached by email and telephone by one of the authors (TH) in the period from May to June 2019. In three cases the questions asked were answered by email. The remaining 18 interviews were conducted by telephone. The duration of the telephone interviews varied from 40 to 90 minutes. The author (TH) wrote down the answers during the interview and then summarised them. Each interview was sent to the interviewee for approval and/or supplementation, after which it was recorded and saved. All interviewees agreed with these summaries, in some cases after certain clarifications.

The interviewees are healthcare administrators, patients, doctors, health insurers, business people working in the healthcare sector, researchers, consultants and winners of the [VBHC Prize](#). All were familiar with the VBHC concept and had long-standing experiences with initiatives in this field. Some interviewees appreciated remaining anonymous in the report for reasons of their own. Hence, no list with the interviewees' full names has been included in this paper.

The answers to the questions were compiled afterwards and divided into a number of overarching categories. A total of 57 unique, distinctive answers were given. The categorisation was done on the basis of common denominators recognised and considered relevant by the authors. Given the small numbers of interviewees per professional group, no breakdown has been made by the background (director, consultant, etc.) of the interviewee.

During the interviews many examples were mentioned, some of which were an elaboration of a point made, some an example from practice. The answers, observations and opinions reflect those of the interviewees and do not have to match those of the authors of this paper.

## Results

The results of the interviews show in summary the underlying problems as mentioned here. The results are presented in six overarching categories, each divided into specific problem topics.

### 1. Insufficient knowledge of what and who is of value to the patient

- a. Not a good view of the (entire) patient

- b. Limited knowledge about the effectiveness of treatment for patients
- c. The core of care, to help patients, has been reduced
- d. Patients do not get the best doctor/care provider.

### 2. Skewed proportions

- a. Patients are not seen as (equal) discussion partners
- b. Limited commitment from the patients themselves
- c. A doctor is still rather a 'God' than a 'Guide'.

### 3. An economically unfavourable picture

- a. Discrepancy between economic input and outcome
- b. No good knowledge of actual costs
- c. Funding rewards Volume, not Quality.

### 4. Insufficiently informed patients and employees

- a. Insufficient information hinders patients in their choices
- b. No unambiguous language
- c. Insufficiently informed healthcare workers.

### 5. Inadequate business operations

- a. Disjointed, fragmented, scattered care
- b. Blind spot for healthcare processes in doctors
- c. Own interests
- d. Moderate internal organisation
- e. Lack of motivation, mutual trust; dissatisfied employees
- f. Limited external coherence.

### 6. Limited learning and change ability

- a. Inadequate focus on innovation, on improving care outcomes
- b. Existing culture inhibits change.

## Discussion

Since the 1990s, according to an analysis by BCG consultancy, the gap between healthcare expenditure and the disposable income of citizens has widened worldwide (Boston Consulting Group 2007). This also applies to the Netherlands. Healthcare institutions notice this through imposed spending ceilings and cutbacks. The traditional response of healthcare institutions to this is typically focussed on the short term, often on solving the financial issues through structural solutions, cutbacks and/or by performing more transactions. Due to growing external regulations, stricter bureaucratic procedures, and in the absence of a strategic course based on conviction, ambition and realism (which is recognisably carried out and guided during implementation), it is difficult to turn this tide (van Merode and Brouwer 2020). The patients do not seem to play a role in this traditional approach. Moreover, the enthusiastic caregivers, the inspired ones, often become frustrated and drop out. This interview study shows that, according to the experts consulted, there is much more going on.

### **Insufficient knowledge of *what* and *who* is of value to patient**

There is insufficient knowledge among healthcare providers about *what* and *who* is of value to the patient. For example, care providers do not have a view of the (entire) patient. There is limited knowledge about the effectiveness of treatments for specific patients, but more for 'averages', which makes it difficult to distinguish between sensible and nonsensical care. Effectiveness and what is of value to patients are primarily defined from a clinical perspective, rather than from a patient's. The core of healthcare institutions, namely to help patients, is gradually slowing down. And patients do not vote by feet, neither they automatically get the best doctor, partly because it is hard to tell who the best doctor is.

### **Skewed proportions**

There are skewed relationships between patients and healthcare providers. On the one hand, patients are not seen as an (equal) conversation partner by the care provider. On the other hand, patients themselves often show limited engagement. The much-described movement by the doctor from 'God' to 'Guide' has only started to a limited extent (Britnell 2013). The doctor is still considered as the great knowledge bearer. The consultation room is not yet a safe environment for patients to have an open conversation with the doctor in their role as partner-coach about the quality of care and their lives.

### **Economically unfavourable picture**

This is due to a discrepancy between the resources we put into care (time, people and money) and the results, such as adequate diagnostics, treatment and achieved health outcomes. Both the World Health Organization (WHO) and the OECD estimate that up to 30% of the resources deployed are wasted on avoidable complications, unnecessary treatment or administrative inefficiency (WHO 2018). Healthcare providers and managers also lack good knowledge of the actual costs per care cycle of diagnostics, treatment and monitoring. This prevents the (rising) costs from becoming transparent and makes it possible for duplication of work to continue. Current financial flows focus on volume, not quality, and thus stimulate volume growth. It also indirectly creates a 'right' for physicians to determine treatment. It rewards bad treatments, pays for duplicates, and encourages over-treatment and unnecessary, but billable, transactions. After all, fewer treatments often means less income.

### **Insufficiently informed patients and employees**

A lack of transparent, relevant information is a major problem because it prevents patients from choosing the

healthcare provider or treatment that is best for their specific situation. It is precisely at the start of their illness that patients are often ignorant. Not being able to determine patient-relevant health outcomes deprives them of the opportunity to determine where they can best go. Data on outcomes for medical conditions are difficult to compare because data (infrastructure) are not interconnected and no unambiguous language is used. Furthermore, privacy regulations form another barrier to interoperability. To be able to deploy the best treatment process for each patient, care professionals need a clear understanding of treatment outcomes and experiences. Without that healthcare professionals miss opportunities to identify and monitor possibilities for improvement.

### **Inadequate business operations**

Healthcare is characterised by inadequate operational management and is primarily organised from the perspective of the doctor and the care institution, not from the patient's perspective.

This has its roots in the classic image of the doctor who 'knows everything' and is personally involved in the care of their patients. Organising the care around the doctor was at that time logical. Today there are many more disciplines and sub-specialities, which results in fragmentation of the healthcare offering and less insight into the cohesion of care for the entire patient. Doctors have blind spots for care processes of their own patients, and for what happens outside their immediate speciality or outside the walls of their institution. This results in duplication of work, which is unnecessarily burdensome for all those involved. Doctors have their own interests, specialities, way of working, and specific wishes that do not have to be well-attuned to the value interest of the patient. The current structurally subordinate role of the nurses does not help with this (van Merode and Brouwer 2020). The enthusiasm in the workplace has decreased, partly due to the aforementioned fragmentation, to suboptimal and bureaucratic care. Employees are often not involved in the direction of their institution, in analyses of specific patient groups, in treatment considerations and improvement initiatives, which results in a decreasing sense of responsibility, accountability and changeability (Hanselaar 2020). Healthcare professionals have shown during the COVID-19 crisis that with focus, dedication and expertise they are able to realise major adjustments in the short term. There is capacity for change in healthcare, but little is used. Apparently, given the experiences during the crisis, addressing doctors and other care providers about their professional responsibility can be helpful in this respect.

There is little national cohesion in the collection of data and in analysis of patient groups. Joint benchmarks are struggling to gain ground. Exceptions such as Measurably

Better, ([Meetbaar Beter](#)) are limited in number. Partnership with the business community is still insufficiently available. The realisation that if a contribution from, for example, pharma is good for the patient, it can also be good for the pharma company, must still grow mutually. This is necessary to achieve better results together.

### Limited learning and change ability

Parties in healthcare are not specifically focussed on improving the outcomes in healthcare. Academic medical research often does not look into applications or improvements in practice. Medical teams find it difficult to recognise and utilise their potential for improvement, as individuals or as a team. This and the limited application of innovations in healthcare are an expression of an internal organisation that is poorly aligned with patient value creation. Because there is no joint outcome perspective, there are no options for identifying improvement of outcomes and monitoring results. Only limited attention is paid to best practices. There is also little incentive to do this due to a limited R&D budget. The existing, ingrained culture in healthcare is difficult to change, both among healthcare professionals and patients. This could be partly out of fear of deterioration. It is in the nature of people, and it will not be very different in healthcare, to fight harder for the preservation of something than to acquire something new. Healthcare professionals often have a wait-and-see, sometimes lethargic attitude towards changes in culture and behaviour. In effect, the existing culture is more likely to inhibit change than to stimulate it.

### Conclusion

With the overview presented here, we aim to provide care givers, innovators and policymakers who would like to start or have started a VBHC initiative, with an insight into the problems that play a role in healthcare. But we also want to inform those who have not (yet) come into contact with VBHC with the answers to the question about the type of problems that are identified in healthcare. According to the experts consulted, the aforementioned problems, challenges if you like, can be solved by applying the VBHC concept. By organising the activities for the patient well and in cohesion, with the aim of better outcomes for the patient, teams can create patient value. However, care is not currently organised like this, and this is at the root of the problems in care. Worse still, the rules and funding oppose this way of working. In a subsequent paper we will show which success factors according to these experts can help the implementation of value-driven care and which can make care for patients outcome-oriented and cost-conscious.

### Conflict of interest

No conflict of interest reported. ■

## Appendix

### Value-Based Healthcare Model

The VBHC definition of value in healthcare is presented in a ratio:

$$\text{value} = \text{outcomes} / \text{costs}$$

In this value ratio, the numerator (outcomes) indicates condition-specific outcomes that are most important to patients, such as functional recovery and quality of life, while the denominator (costs) applies to the total expenditure for the entire care cycle (Porter and Teisberg 2006). Thus, if the results important to patients are not improved, the resulting value is low.

This definition applies to the entire care pathway, from primary to secondary and tertiary care, including post-hospital care for patients with a single disease or comorbidities. VBHC essentially wants to offer care for patients in such a way that (health) value for the patient is delivered in an acceptable proportion to the costs incurred (Kaplan and Anderson 2004).

The key VBHC concepts are:

- specific medical conditions/patient groups
- integrated multidisciplinary treatment teams
- (medical) leadership
- outcome measures
- patient-doctor relationship
- process design
- IT platform
- dashboard
- actual activities cost
- improvement initiatives
- bundled financing
- regional network relationships
- transparent information.

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# “But I Hate This, and This, and This...”: Body Dysmorphic Disorder

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Body Dysmorphic Disorder (BDD), a psychiatric illness characterised by an obsessive and debilitating preoccupation with perceived physical flaws, carries a significant burden of morbidity. Currently, there is little research investigating methods for the effective early detection, diagnosis, and treatment of BDD. In this case, thrombotic microangiopathy may have been a result of the use of unprescribed phentermine in an attempt to self-treat BDD. The early detection of BDD is needed to prevent substance use and many other potential consequences of untreated BDD.

## Case Presentation

This case demonstrates the importance of developing early detection and treatment strategies for BDD in order to prevent comorbidities, like substance use, suicide, anxiety, and depression. Furthermore, this case reveals the paucity of current literature surrounding the use and safety of phentermine and draws attention to the need for additional research on phentermine use if physicians are to continue prescribing this drug safely. This case report is an initial step in illuminating the dire need to bridge such knowledge gaps, initiatives that are necessary to improve outcomes for afflicted patients.

A 46-year-old woman presented with progressively worsening migraines, menorrhagia, epistaxis, and fatigue. A thorough history revealed the patient’s perseverance on her abdominal girth, as well as her usage of unprescribed phentermine and other stimulants for weight loss. Laboratory studies revealed low haemoglobin (9.9 g/dL) and platelet count (57 k/ $\mu$ L), low prothrombin time (10.5 seconds) and INR (0.9) values, and a high creatinine (14.90 mg/dL) (Table 1). Schistocytes were noted on peripheral blood smear, and a renal biopsy revealed thrombotic microangiopathy with patchy acute tubular necrosis and mild hyaline arteriosclerosis (Figure 1). The patient had a full recovery after 1.5

rounds of plasmapheresis, one unit of packed red blood cells, and regular haemodialysis. The aetiology of the thrombotic microangiopathy was never discovered and was suspected to be a result of over-the-counter phentermine use.

At the one-month follow-up appointment, the patient asked her physician if she could resume taking 5-hour energy shots and a weight loss supplement she had found online. She was strongly advised to avoid these substances. Two months later, at her next follow-up appointment, the patient was well with no acute complaints. Again, she inquired about taking a ketogenic weight loss supplement, which she was advised against. No specific treatment plan was initiated to address her diagnosis of Body Dysmorphic Disorder.

## Introduction

Body dysmorphic disorder (BDD) is a psychiatric illness characterised by an obsessive focus on personally perceived flaws in one’s physical appearance. The level of obsession observed in patients with BDD differs from common appearance-centric concerns in that it causes impairment in daily life and even extreme distress (Atmaca et al. 2010). Symptoms typically manifest in early adolescence and often involve hours of obsessive



	Patient Value	Normal Value
Hgb	9.9 gm/dL	12-15.5 gm\DL (women)
PLT	57k/ $\mu$ L	150-450 k/ $\mu$ L
Cr	14.90 mg/dL (0.9 mg/dL in March 2017)	0.5-1.1 mg/dL
PT	10.5 sec	11.13.5 sec
Fibrinogen	343 mg/dL	150-400 mg\DL
Peripheral Blood Smear	+Schistocytes	-

Table 1. Patient Lab Values. The patient presented with bicytopenia of red blood cells and platelets, elevated creatinine, and schistocytes on peripheral blood smear, suggesting a thrombotic microangiopathy.

and repetitive behaviours, such as checking one's appearance in mirrors or picking at the skin (Gunstad and Phillips 2003). The aetiology of BDD is complex, but biological factors, such as abnormalities within the orbitofrontal cortex and anterior cingulate cortex, are implicated, as well as socio-environmental and psychological factors (Atmaca et al. 2010). Women tend to obsess about their skin, stomach, weight, breasts, and thighs, while men are more likely to obsess about their genitals, muscle tone, and hair thinning (Phillips et al. 2005; Wilson and Arpey 2004).

Despite recent interest in BDD and a general population prevalence between 1.7% and 2.4% in 2017, there is little research available on how to effectively recognise or diagnose affected individuals (Jawad and Sjögren 2017). This has facilitated the under-diagnosis of BDD, a disorder that, when left untreated, can have grave, negative sequelae. Untreated BDD patients have higher rates of depression, anxiety, suicidality, substance use disorders, hospitalisations, and unemployment than their counterparts who receive treatment (Phillips et al. 2005; Jawad and Sjögren 2017; Phillips and Menard 2006). Empirical studies report suicidality prevalence rates that are as high as 80% among BDD patients, as well as suicide attempt rates that are up to 12 times higher than that of the average U.S. population (Phillips and Menard 2006). These statistics illuminate an evident need for focused, effective rehabilitation therapies, yet current data indicate that only 20% of

treated patients report full remission after four years. Furthermore, relapse rates are as high as 42% even after four years of remission, with higher relapse rates occurring in more severely affected patients (Phillips et al. 2013). This evidence portrays the chronic and unrelenting nature of BDD, as well as necessitates early detection to mitigate morbidity.

The patient in this case report, later found to have undiagnosed and untreated BDD, began taking unprescribed phentermine as a consequence of her preoccupation with her body weight. Phentermine hydrochloride, trade name Adipex-P, is a sympathomimetic amine anorectic indicated for clinical use only as a short-term adjunct in weight loss regimens for the treatment of exogenous obesity (FDA drug information 2012). Eligible patients should have a body mass index  $\geq 30$  kg/m<sup>2</sup>, or  $\geq 27$  kg/m<sup>2</sup> if other risk factors (i.e. diabetes mellitus, hyperlipidaemia, controlled hypertension) are present (FDA drug information 2012). The U.S. Food and Drug Administration (FDA) recommends an individualised risk-benefit analysis for each patient before prescribing phentermine, as there are many risk factors, known and unknown, assumed with phentermine use (FDA drug information 2012). Despite these cautionary warnings, phentermine is commonly abused by patients with eating disorders or those wanting to achieve weight loss (Thomas 2015). Further research into the role that phentermine may have played in this woman's clinical presentation revealed a paucity of literature investigating the mechanism of

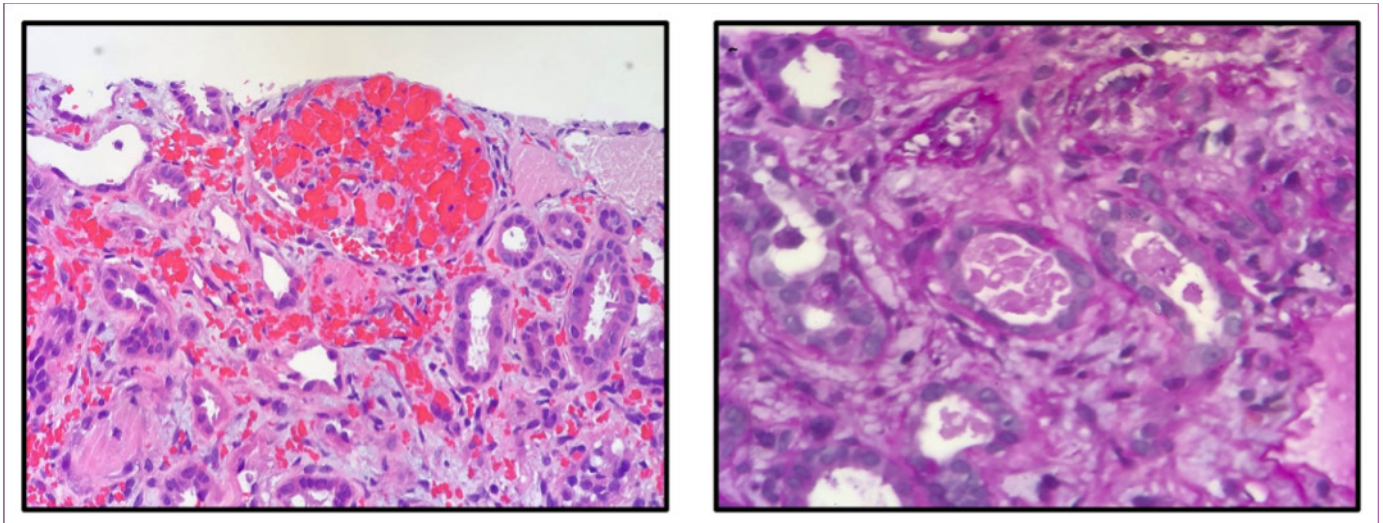


Figure 1. Renal Biopsy Histology. Renal biopsy showed acute-on-chronic thrombotic microangiopathy with patchy acute tubular necrosis and mild hyaline arteriosclerosis. No specific glomerular immune deposits or light chain restriction were seen by immunofluorescent microscopy.

action or adverse effects of phentermine. Phentermine was approved by the FDA in 1959, a time when fewer drug regulations and restrictions existed. As such, there is still very little information about phentermine use that has been elucidated from formal trials and research studies (Thomas 2015).

### Discussion

BDD remains under-researched and under-recognized. This case report demonstrates one of many potential downstream comorbidities that can result as a consequence of untreated BDD: substance use. The patient in this case study was using Phentermine in an unprescribed and unmonitored manner for weight loss. With no other ready explanation for her DITMA diagnosis, phentermine use must be speculated as a potential cause. The patient was also taking additional stimulants, including Adderall, 5-hour energy drinks, and caffeine, in an unregulated manner. Ultimately, this case report is problematic for two reasons: 1) too little is known about phentermine to either correlate or negate its involvement in the unknown etiology of this patient's thrombotic microangiopathy, and 2) the early diagnosis of BDD in this patient may have prevented her substance use and subsequent clinical presentation.

The FDA approved phentermine for market in 1959 under a set of regulations and restrictions far different from those upheld today (Thomas 2015; [fda.gov/about-fda/fdas-evolving-regulatory-powers/milestones-us-food-and-drug-law-history](http://fda.gov/about-fda/fdas-evolving-regulatory-powers/milestones-us-food-and-drug-law-history)). Several potential adverse effects of phentermine use have been identified in the cardiovascular, gastrointestinal, allergic, central nervous, and endocrine systems. A few of the more serious potential adverse events include primary pulmonary hypertension, regurgitant cardiac

valvular disease, ischaemic events, and psychosis. Furthermore, phentermine use is contraindicated in patients who are taking other weight loss drugs, even those that are prescribed (FDA drug information 2012). The FDA does not explicitly define DITMA as a potential adverse effect of Phentermine use, and there are no previous case studies describing any similar presentations. Thus, phentermine's implication in this case study is of critical importance and calls for further investigation of phentermine's mechanism of action and potential adverse effects to ensure the safety of patients.

As a whole, substance abuse disorders constitute the second most common lifetime comorbidity for BDD patients, behind major depressive disorder (Grant et al. 2005). In a study assessing substance abuse disorders in 176 subjects with BDD, 48.9% of the subjects suffered from a substance abuse disorder: 42.6% from an alcohol-use disorder and 30.1% from a cannabis-use disorder. Of these subjects, 68% reported that BDD contributed to their substance use, and 30% of the subjects cited BDD as the "main reason" or a "major reason" for their substance use (Grant et al. 2005). Stimulants and weight loss drugs were the substances used by the patient in this case report, but it is important to be aware of the possibility of any substance use/abuse in BDD patients and to consider how this might be affecting their health and treatment plan.

Substance use/abuse, and the physical maladies that may occur as a result, are only the beginning of a long enumeration of consequences that can occur when BDD remains undetected and untreated. BDD patients spend at least one hour per day focusing on the aspects of their appearance that they perceive negatively; 40% of BDD patients spend 3-8 hours per day on these concerns,

and 25% of patients spend 8+ hours per day. This leads to impaired psychosocial functioning, severe anxiety and distress, and poor quality of life (Bjornsson et al. 2010). In fact, patients with BDD have been shown to have a poorer quality of life than patients suffering from diabetes mellitus or clinical depression (Phillips 1999). In a U.S. population study on BDD patients, it was found that they were less likely to be married and more likely to be separated from their partners (Koran et al. 2009). Furthermore, the occupational functioning of BDD patients is often diminished. A study of 141 adults with BDD ascertained that 39% of the subjects missed work secondary to psychopathology from their BDD diagnosis, and 79.7% reported impaired functioning while at work for the same reasons (Didie et al. 2008). Most concerning is the high rate of suicidal ideation and suicide attempts in BDD patients. In a study with 200 BDD patients, it was reported that 78% had lifetime suicidal ideation, and 27.5% of the patients had actually attempted suicide. Most of these patients revealed that they did not disclose their BDD symptoms to their physicians (Phillips and Menard 2006).

This segues into one of the most actionable aims of this case report: physicians need to understand the importance and necessity of recognising and detecting BDD in their patients as early as possible, in order to alleviate the burden of morbidity faced by these patients. One study determined that 15.1% of patients did not discuss their BDD symptoms with their physicians (Conroy et al. 2008). Moreover, in the culmination of five different studies in which adults were screened for BDD, it was found that none of the patients found to have BDD had the diagnosis in their medical record (Bjornsson et al. 2010). The physicians that need to be most aware and cognisant of the potential for BDD are dermatologists, otorhinolaryngologists, and plastic surgeons, as BDD patients most frequently turn to them for cosmetic procedures (Lahousen 2015).

There are several techniques available for the early detection of BDD, including visual assessment, questionnaires, and interview tactics. Patients with BDD often present with abnormal or aggressive behavior and unrealistic

expectations that an aesthetic operation will completely fix their perceived blemish. This is often accompanied by disdain and dissatisfaction with previous physicians who have operated on their perceived flaw in the past. BDD patients will often search for confirmation of their blemish and may have developed excessive methods of camouflage to cover the perceived flaw [i.e. makeup, concealing clothing, hair styles, etc.] (Lahousen 2015). Physicians should pay special attention to patients who continue to request different cosmetic procedures and either express dissatisfaction with the results of a procedure or immediately begin lamenting another specific feature of their appearance. Additional behaviours common to BDD patients include skin-picking, immoderate tanning, and excessive doctor's appointments (Wilson and Arpey 2004).

If these behaviours are observed in a patient, several questionnaires have been developed to assist physicians and patients in recognising BDD. The Body Dysmorphic Questionnaire (BDDQ) and Cosmetic Procedure Screening Questionnaire (COPS) for Body Dysmorphic Disorder are guides that have been verified as having significant results in the use of identifying BDD patients. The BDDQ is based on the DSM-IV criteria for the diagnosis of BDD and has been shown to have 100% sensitivity and 92% specificity in a dermatologic setting. The COPS Questionnaire is available on the Body Dysmorphic Disorder Foundation's website, available to the public to aid in the self-recognition of BDD. It cautions that only physicians can make an official diagnosis of BDD, but it is helpful for use as a screening tool ([bddfoundation.org/helping-you/questionnaires/](http://bddfoundation.org/helping-you/questionnaires/))

It is exceedingly important that physicians actively attempt to recognise BDD and utilise these tools to aid in the early diagnosis of BDD. With the intentional efforts of physicians, it can be recognised and treated early, mitigating the burden of morbidity and improving the quality of life for patients afflicted with BDD.

### Conflict of Interest

None. ■

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# Shared Journey Towards People-Centred Health Systems

## From narrative to action

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The one and only reason that health systems exist, is to make a positive contribution to the lives of people using them. Surprisingly, we still cannot tell to what extent they succeed in this mission. There is strong interest among patients, healthcare providers and policymakers to transform our health systems, with the objective of putting people at their centre and continuously improving their lives. We have talked enough and it is time for action.

### Key Points

- Economies in the OECD are spending 10% on average on healthcare, but we know little about what exactly we get back for this large investment.
- Although there are massive amounts of data on healthcare, few of these data tell us to what extent health systems make peoples' lives better.
- The relevance of getting systematic insight in the outcomes of healthcare as reported by patients is widely acknowledged.
- Countries across the globe are now joining forces and working together to make the step towards a new generation of health statistics: patient-reported outcomes and patient-reported experiences.
- The systematic measurement of patient-reported indicators is an essential step towards people-centred health systems.

### What Do Health Systems Deliver?

Countries across the OECD spend close to 10% of their Gross Domestic Products on health. Looking at both the demographical and epidemiological projections, and the emergent health needs such as the threat of pandemics, this percentage will continue to rise in the coming years. This puts emphasis on one question: what exactly are health systems delivering to people using them? In the past two decades, the body of literature on health systems performance, the number of performance indicators and the amount of benchmarking exercises has grown in most OECD countries. Despite the useful insights that these approaches generate, one pivotal aspect is often painfully absent: the perspective of the patient.

Healthcare activities generate a lot of data: there are international standards for the recording and calculation

for healthcare costs, diagnoses, hospital admissions, prescriptions, mortality and many others. Such information is essential intelligence for policymakers, funders and providers of care and should be used fully. However, as comprehensive as they are, none of these data touches on the very essence of healthcare: *does it make patients' lives better? Does healthcare improve what really matters to patients? How do patients experience the care they receive? Do they feel ready and empowered to manage their conditions and take good care of their health?*

The inability to answer such vital questions is problematic: until the returns on investments in health can be stated more clearly, policymakers will be flying with little guidance to direct decisions on the mobilisation and use of resources. In addition to massive human suffering and loss of lives, the COVID-19 pandemic has laid bare many



vulnerabilities of health systems. Older people and people living with chronic conditions are impacted most, but their health systems know very little whether they have what they need to better manage their health needs.

Slowly but surely, a paradigm shift is taking place in the way we think about healthcare, with a focus on the people who use it. Policymakers, academia, healthcare providers and patients are joining forces to make health systems more people-centred. The willingness is there, now it is time to walk the talk, and the COVID-19 pandemic has only made this effort even more urgent. Making this a shared effort is the only way forward.

### Patient-Reported Data in Policy and Practice

The use of Patient-Reported Outcome Measures (PROMs) is no novelty in clinical settings. There is an abundance of available instruments to measure PROMs, and their use has become increasingly common. Healthcare providers are intrinsically interested in how their patients are doing. PROMs tools can help fostering a constructive dialogue between patient and provider, and help tailoring care to their needs. Moreover, providers can learn from each other by comparing results. Examples of patient-reported outcomes that hugely impact people's lives are levels of pain, mobility, the ability to participate in social activities, and anxiety. However, the ability for policymakers to capitalise on existing data collections has been limited so far, for several reasons.

that providers may be judged based on unfair comparisons, resulting from flawed or insufficiently standardised data, and that 'getting the figures right' may become a goal in itself, with the risk of manipulation. In such cases, the debate may quickly move away from ways of providing the best care for patients towards a discussion about money, reputational damage, or an everlasting methodological discussion.

### International Effort

The world-famous Parisian Victor Hugo said that nothing is more powerful than an idea whose time has come. Indeed, policymakers, patients, healthcare providers across the globe agree that health systems need to change; from health systems that are centred on supply and 'curing illness' to health systems that are centred on people's individual needs and well-being. The question is not so much 'if' but *how* this should materialise. This fundamental change has important implications for how we measure health system performance.

During their Health Ministerial meeting in 2017, health ministers called on the OECD to lead the development of a new generation of health performance measures and to support countries in implementing them (OECD 2017). Today, countries inside and outside the OECD have joined forces in this international effort called the Patient-Reported Indicator Surveys initiative ([PaRIS](#)), and first data collection will commence in 2021.

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## Healthcare activities generate a lot of data. However, none of these data touches on the very essence of healthcare: *does it make patients' lives better?*

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First, the variety of tools and initiatives has created a situation of 'many flowers blooming'. Even within the same country measurement practices vary, and internationally the ability to compare is limited.

Second, PROMs are mostly used in hospital settings and typically apply to curative, episodic situations with a clear 'before and after' the intervention. Hip and knee replacements are typical examples. However, there is a large, and growing, group of healthcare users who live with chronic conditions and receive healthcare in primary care settings for years or even decades. In such cases, there is no 'before and after'; their healthcare is a continuous process.

Third, as soon as the collection of patient-reported measures becomes a national undertaking, focussed on public benchmarking or accountability, the interest of healthcare providers may be reduced. Common concerns are

In the past years, the OECD has had intensive dialogues with leading experts across the globe to make a feasible plan for this ambitious undertaking. To overcome the challenges as mentioned above, two key principles are leading in the PaRIS initiative: inclusive development and alignment with national directions.

### Inclusive Development

A continuous dialogue between governments, patient groups, health professionals, payers and other key stakeholders in the industry is essential to move forward. This is complex and time-consuming. However, there are no short cuts; all these perspectives are necessary and change requires joint work. To illustrate this with two examples: although patient involvement in the development of patient-reported measures may seem obvious, studies have

shown that many such instruments were developed without any patient involvement or with minimal involvement of patients. The OECD has established an international panel of patient organisations, including international umbrella organisations such as the NCD Alliance and the European Patients' Forum, to advise on crucial steps and ensure that PaRIS data will truly reflect elements that matter to patients.

Moreover, most healthcare providers are keen to know more about the outcomes and experiences of their patients, because they want to improve their quality of care. Excluding providers from the development process would have been a missed opportunity, and they would see little value in receiving a tool developed without their inputs. Therefore, the OECD consults provider organisations and international networks of providers in the development process of PaRIS. This guarantees that PaRIS will generate information that helps providers improve healthcare. PaRIS will enable providers to compare aggregated results with those of their peers, in an anonymous format, and identify ways to continue improving their practice.

### Alignment with National Directions

Health systems are organised in different ways across countries. Some are more centralised whereas others have regionalised structures. Some have primary care providers as gatekeepers for secondary care whereas other systems offer more direct access. Maybe even more important is that many countries have already ongoing initiatives, in which patient-reported measures are collected, through national or local surveys, clinical registries, or other initiatives.

Although this may pose a challenge for the development of international standards, the PaRIS initiative actually benefits from the richness of national and local expertise. The development of the flagship project of the PaRIS initiative, the International Survey of People Living with Chronic conditions, already includes 17 countries. This survey focusses on people with chronic conditions who live in the community and whose conditions are mainly managed in primary care settings. The development and implementation is supported by an international consortium of academics and one of the industry leads in international survey research. This will be the first-ever international survey on patient-reported measures of this scale.

One of the driving forces of PaRIS is that rather than imposing a new standard, countries work together to find the common ground in the collection of patient-reported measures for specific conditions and discuss how best to align their data collections to facilitate international learning. In addition to the survey of patients with chronic conditions, international condition-specific working

groups are hard at work, such as the breast cancer working group, with nearly 100 participants representing countries and clinical registries. Similarly, the working group for hip and knee replacements includes 16 countries and international networks such as the International Society of Arthroplasty Registries (ISAR) and the World Confederation for Physical Therapy (WCPT).

### Next Steps Towards More People-Centred Health Systems

One of the most important sayings in organisation theory is that if you can't measure it, you can't improve it. The international collection of patient-reported measures is a necessary step to take on our shared journey towards more people-centred healthcare systems; health systems that are organised to support people in those aspects that matter most to them. There is no other purpose of health systems than serving patients. Patient-reported measures are no 'soft data'; they must be measured in a valid, rigorous way and developed together with all stakeholders at the table. It is not about fees, it is not about bar charts and league tables, it is about the lives and well-being of patients.

### Conflict of Interest

The authors declare that they have no competing interests. ■

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# The Business Case for Person-Centred Care

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While some choices in healthcare may be limited due to circumstantial urgency, more often than not, patients and family members hold a significant position to influence the trajectory of their care. Especially in recent years, with the advent of new technologies and sharing platforms, patients are now better equipped to explore options, fact check, review performance and optimise their choice in care. Healthcare consumerism implies that people are leveraging tools to make informed choices about the goods and services they purchase. Healthcare organisations, in turn, must meet this new demand by adopting a person-centred approach to set themselves apart as capable of being an equal partner with patients and family members throughout their emotionally and physically turbulent journeys.



## Key Points

- Patients and family members are increasingly equipped with tools to facilitate involvement in their care.
- Organisations that seek to set themselves apart must develop strategies to meet these new demands.
- A person-centred culture within healthcare organisations would facilitate healthcare delivery that is aligned with patient demands.

The healthcare industry is unlike any other. Politics and economics are heavily involved, health decisions impact every aspect of life, every individual has some interaction with the healthcare system at some point in their life, and the choices we make throughout our lives influence the extent to which we interact with the healthcare system. However, one reason in particular lends to the unique position of the healthcare system: limited choice due to urgent circumstances. No other industry limits choices due to immediate need to the extent of the healthcare system. Consider the emergency patient who must have surgery by the on-call surgeon, or the pregnant woman who goes into labour and the OB of her choice is not on call. While the emergency circumstance is unavoidable, the peri-circumstantial choices made by the patient and the general public can have significant influence on the healthcare system.

Where they do have 'choice' is in compliance with care plans. Patients can choose whether they will fill prescriptions, take medication as directed, quit smoking, and keep their follow-up appointment. They can also choose to seek out information online, which may or may not be accurate. These 'choices' have an impact on healthcare in a way that no other industry experiences. As healthcare organisations become increasingly responsible for improved outcomes, these 'choices' can negatively impact reimbursement and the financial health of the organisation.

Consumerism in healthcare implies that people are making informed choices about the goods and services they purchase. The role of healthcare organisations is to help patients make informed choices and to choose to adopt their plan of care. This means creating person-centred care models that involve the patient and family



as equal members of the care team and working towards systems of high reliability to ensure continuity of messages delivered to the patient.

The accessibility of information to patients and the general public is one of the primary motivators for hospitals to act in accordance with how they desire their representation. With the increasing mobile accessibility of information in nearly every discipline, from bank information to wedding planning, there is an increasing expectation of accessibility of health information including but not limited to files and patient data. The information that historically remained covert is now more readily accessible and, as such, consumers are better able to detect the subtleties in hospital offerings and shortcomings when comparing facility to facility.

In addition, healthcare providers should expect now, more than ever, that they will be ‘fact-checked’. This anticipation should prompt the development of systems to ensure reliability and integrity of information between providers, and providers and patients. The near-immediate speed at which information is shared and disseminated allows little room for mitigation of the mistake after it has occurred. Instead, hospitals and healthcare systems need these processes in place to avoid the mistakes, and immediate publicity of the mistakes, in the first place.

Furthermore, individuals’ interactions with the healthcare system are often immensely emotional and physically and mentally rigorous. People choose experiences that are pleasurable, seamless and genuine, especially when it comes to their healthcare. Patients will choose visits with providers with whom they feel connected, those with whom they can have a conversation, those who include them and their family members as key partners in care, and those with whom the integration into all clinical conversations is genuine and encouraged. Therefore, those organisations

that embody a culture of safety before the patient even arrives, through, for example, community engagement events or an organised network of outpatient providers, will elevate the standard of care and set themselves apart. Once the patient selects that hospital for care, and the culture of safety and person-centredness is reinforced throughout the continuum of care, the patient will share their positive experience post-discharge.

Similar to the accessibility of objective hospital information, patients are able to access subjective feedback about the hospital at their fingertips. Much like the Amazon model, hospitals and healthcare organisations are informally ‘ranked’ by their patient population online or via social media, thereby influencing future patients’ decisions for care and treatment. It is more likely that people will share an experience of dissatisfaction than a positive experience. In fact, it has been shown that 45% will share a negative experience on social media while only 30% share the good (Dimensional Research 2013).

In recent years, and especially with the advent of COVID-19, patients are more primed than ever before to be sceptical of their care due to the accessibility of the internet (and the accessibility of potentially false or dissonant information). Therefore, hospitals must ‘prove themselves’ right out of the gate. This proof cannot be accomplished with a facade that behaves as a switch when someone is ‘watching’. Instead, this proof must be generated through systems of high reliability that took years to establish within the organisation.

Future considerations to improve patient experience should include:

- Emphasis on person-centred care
- Incorporation of the patient and family members as active parts of the care team
- Increased accessibility of patient data and expansion of patient portals
- Improved care coordination to ensure effective communication across the continuum.

There are several quality and safety organisations that advocate for patients to become their own care coordinators. Healthcare leaders need to anticipate this patient-driven demand for inclusion in their care and care decisions. The Patient Safety Movement Foundation offers free resources to guide clinicians and administrators in setting themselves apart in the healthcare space and to empower patients and the general public to take ownership over their health and care decisions.

### Conflict of Interest

The authors declare that there is no conflict of interest. ■

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# Is Patient Really Empowered in Medical Industrial Complex?

Author: [Peter Kapitein](#) | Patient advocate | CEO | Inspire2Live | Amsterdam | the Netherlands

A veteran patient advocate questions some of the hyped patient-engagement concepts and the reality of their practical applications within the ‘medical industrial complex’, and offers some strategies to change ‘the way we work’.



## Key Points

- In the medical industrial complex, stakeholders are distracted from the essence, i.e. the patient.
- There are many obstacles on the way to change, from the lack of money to disruptions in data flows.
- The notions of responsibility and ‘problem ownership’ should be brought into healthcare.
- Bringing together different stakeholders, creating the supportive environment, finding the root causes and working independently are key success factors on the way to patient-centred healthcare.

It may give us a pleasant feeling to think that the patient is well-informed, engaged and empowered. But I don’t think they are. With this in mind and due to another hype – ‘patient centricity’ – it makes me think of the Hollywood movies. When the director needed an Indian to get a shot of his pony, he shouted, ‘Go get an Indian!’ It’s the same with healthcare (or science that tries to help healthcare). When we explore new initiatives or set up projects in healthcare, we suddenly need a patient (‘Go get a patient!’) to fulfil the requirement that we really met one and had a discussion with them. In the end, the door closes and the decision is made in the same room by the ones who have always made the decisions over the past decades.

Most people feel uncomfortable to change their way of working and to change the balance of interests in the medical industrial complex (Kapitein 2018). Let me explain.

### Medical Industrial Complex

1962. In his farewell [address](#) to the nation, President and General Eisenhower made us aware of the military industrial complex.

*Armed forces, government and industry, working together in a way that doesn’t necessarily benefit the safety of the American people. Beware of the medical industrial complex.*

This was his message (my interpretation, you can watch his address on YouTube). This is a message and a warning from one of the most respected generals and presidents of the United States of America. He should know.

Ever since, more industrial complexes have grown. One of them is the ‘medical industrial complex’. Patient organisations, doctors, scientists, industry, government and health insurance companies/payers work together in a way that does not necessarily benefit the patient. I think there is no bad intention in this. It’s ‘the way we work’.

All industrial complexes suffer from distraction from their essence. This can relate to anyone or anything: the citizen’s safety, the army, the owner of a savings account, bankers. In the medical industrial complex there is distraction from the patient. Again, this is unintentional, but it happens. The further you are away from patient, the easier it is to make decisions that benefit your own interest and harm the patient’s benefit, which is quality of life. In this, there is a great difference, for example, between the empathy of a nurse and of an industry shareholder.

### Obstacles to Changing ‘the Way We Work’

The obstacles usually in discussion to overcome ‘the way we work’ are money, legislation, providing patients with better data and the lack of cooperation in healthcare. I think these are true and realistic.

- We lack money: but let us not forget that we spend an enormous amount of money on healthcare. There is enough money in healthcare, but the way in which it is spent is the problem.
- Legislation can be a problem: but the way we talk about the GDPR is wrong. The GDPR is designed and implemented to improve the flow of data across borders and between

institutions. And it is possible. Data however, are prevented from doing so by the institutions and the industry that do not want to share; they want to protect their own interests, and use the GDPR as an excuse.

- There are enough data or at least, there are many, but we do not even use the available data. Let's start with sharing and use of the existing data and see what we are really missing. This can be done in parallel.
- Be aware that when you ask patients whether or not you can use their data, they almost always say, 'Yes, you can,' but you do have to ask the question.
- Cooperation between science and healthcare seems to be a problem. Even during the COVID-19 times, we see dozens of initiatives to design, develop and test a vaccine. However, we continue telling each other that competition speeds up the process, even though we know that cooperation does.

These obstacles are valid but not the most important ones. Here are the two major obstacles.

discussions in healthcare and the decision-making process. There is, however, a second hurdle to take.

### Make It Your Problem

Problems in healthcare are not considered to be the patient's. It is the problem of the hospital that is not able to deliver care for COVID-19 patients. It is the problem of the oncologist that they can't help their patient with the right treatment. It's the problem of industry when medicines are not registered and do not get market access. I think that problems in healthcare are the problems of the patient and as long as we, patient advocates, do not act upon this, things won't change or only change very slowly.

Let me give an example. I have a lymphoma and that is my problem. I do need my physician to get over it and get cured, but it is and stays my problem. The same counts for many situations in healthcare. As long as we, patient advocates, tell industry, oncologists, pulmonologists and so

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## In the medical industrial complex there is distraction from the patient. This is unintentional, but it happens

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### Responsibility

Because work in healthcare (and in most industries) is done in a flow, a chain of command, we become a part of these chains and are able to deny our responsibility. We can always say, 'It's not my responsibility, it's theirs, and I am not responsible for the outcome,' or 'The department or group is responsible.'

It was the German philosopher Hannah Arendt who worked extensively on this. In 'Responsibility and Judgment' (Arendt 2005) she explains the difference between legal and moral responsibility. Only this quality distinguishes us from animals: we as human beings have the capacity to think. Not thinking might feel comfortable, but if so, you step away from this important quality of ours. When thinking, we cannot look away from the results of our work, either individual or collective. This is because when we think, we are in a constant dialogue with ourselves. From Socrates we know that we have more problems with doing evil than with undergoing it. This brings in the element of moral thinking and responsibility.

As such, one big obstacle to deal with in healthcare is responsibility. Let's bring it back into our work and behaviour. Looking at the nurse and the shareholder, one might already have an idea on how to overcome this and how to improve the importance of the patient in healthcare; how to deal with changing 'Go get a patient!' into equality in the

on to solve the problem of the patient, it won't be solved quickly. So, when we, patient advocates, take the initiative and create cooperation between the different stakeholders of the medical industrial complex and bring them together, we take the first step towards solutions.

This is only the first, even if an important step. Many more have to be taken. Let's have a look at these.

### How Can These Obstacles Be Overcome?

One answer is value-based healthcare with patient centricity. It is an important step, but it's not enough and it mostly deals with economic aspects in healthcare: 'What's the price of one life year?' – the QALY concept. What we see with COVID-19 is that in an urgent situation this whole concept is thrown overboard. Taking the economic crisis into account, we spend over €20 million per QALY.

Let's look at how I think we can make progress.

### Put Different People in One Room

Back to responsibility. The nurse and shareholder example brings in the idea of 'putting different people in one room'. When we spend time discussing health issues in our own silo (whatever it might be) and have no connection with others, we will mostly consider our own interests. We automatically drift away from the essence

of healthcare: the patient. This doesn't mean that, for example, industry should only talk to patients or patient advocates. (Remember that a patient has a dependency on their physician. A patient advocate is independent and still has a strong bond with the ones they are representing, often a former patient or a loved one of a sick or diseased patient.) It means that industry has to work together with patient advocates, clinicians, regulators, health insurance companies, or payers.

When doing the right thing and doing it well, all stakeholders should work together in the same way as the patient advocate.

How do you get them into the same room?

Evidence is important but not enough. There is so much evidence and science on the shelf. We do not act upon what we already know, and this is preventing us from doing the right thing. In order to bring these ideas to reality, we need to get certain things in place, alongside evidence.

### **Build the coalition of the willing**

Different people should be willing to assist you in your mission, with your project. The ones who are 'willing' are usually easy to find. It is the inner circle you already know, but you also need people with a critical and positive mind. Don't look for the automatic, 'Yes, I agree' type of person. Find the people who criticise you and bring them together to work out the action plan.

### **Build the coalition of the ones who pull the strings**

This is difficult and they are not always easy to find. Some are obvious, like MEPs, ministers, CEOs, project managers, but sometimes it can be the person with a long track record in an institution; it can be the partner of the one who you think is in charge. It takes time to find them and it takes time to involve them in a facilitating and cooperative working position. When you have achieved this, the real work can start. You can gain help in finding these facilitators by asking the people you know in the coalition of the willing. They already know most of them and have an established personal or professional connection with them.

### **Go for Root Cause**

It is important to realise that all stakeholders have their own interests. When industry tells you that their first interest is the patient, this is simply not true. It can't be. Theirs is the shareholders', and this is not unjust. It's a logical consequence of the existence of industry in healthcare. The same counts for scientists: their interest is to deliver science, publish, and find new funding. There is only one stakeholder who holds the patient as their first interest: the patient advocate. The patient advocate places the patient in the centre of healthcare and shows us the reason and essence of what healthcare should

be. Therefore, they ought to be in that room.

When all the stakeholders make clear what their real interest is, it's important for them to know what the other really thinks, even if it makes them uncomfortable. This struggle for betterment and truth moves us forward.

### **Be Independent**

Nobody is independent, but we should strive for it when we want to do the right thing and when we want to do good. You're doing good when you make other people flourish and when you contribute to society, to healthcare and to the quality of life of patients.

It helps to be with different people in that room. It helps even more when you come to a consensus to go for the root cause.

### **Scale Fast**

It's important to start working together on an equal basis and to move forward in a trial-and-error way. Yes, when innovative, you're allowed to make mistakes and by criticising each other in a constructive way, you're able to 'think big, start small and scale fast'.

## **Empowered Patient and Healthcare Systems**

An empowered patient is a well-informed patient. The problem is (be aware that I'm dealing with cancer) that the moment you become a patient you're, by definition, metaphorically illiterate. You become literate during your journey, through life as a patient, but at the start you know almost nothing. Even the doctor who is diagnosed with cancer is helpless in the first moments of their illness. Therefore, the stakeholders in the medical industrial complex have to build a healthcare that promotes excellent care. And we can. I described how to overcome the obstacles, and providing healthcare this way we can arrive at a situation where patients are taken care of in the right way (where quality of life is ranked highly as a state or as a means) and evaluate their care as 'perfect'.

Am I dreaming? Of course, but realism is the biggest enemy of hope, and hope is the energy we all need in life to keep us dreaming and alive. As is love for one another.

### **Conflict of Interest**

None. ■

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# Patient Communication in Radiology - Learning From COVID-19 Experience

Author: [Dr Pilar Manchón Gabás](#) | Breast Radiology | Grup Manchón Medical Director | Affidea Spain Regional Director | Barcelona | Spain

Nothing will be the same after the coronavirus pandemic. The COVID-19 crisis entails an acceleration in some trends like health care digital transformation, the shift from volume-based care to a value-based care and the need of humanising healthcare. Patient communication is in the middle of those three trends and radiology would not be an exception.

## Key Points

- Improving patient communication means higher digital adoption.
- If your product is information, communication is the way to add value.
- Strengthening professional relationships and deepening patient engagement enhances professional satisfaction and helps prevent burnout.

## Digital Revolution in the COVID-19 Era

The “new normal” and the second wave of the pandemic has created a paradigm shift towards digital technology, fuelled by the COVID-19 pandemic. Radiologists now need solutions that alleviate their workload while maintaining the highest levels of precision in imaging interpretation in order to work more efficiently to manage the workload. I especially see an opportunity for artificial intelligence (AI) to speed up the scanning, processing and diagnosis for improving patient care. Solutions that enable automation and enhanced workflow efficiencies that adapt dynamically to rapidly changing circumstances for all the radiology staff and the patients could also be beneficial. I feel the online check-in and fast check-out will be part of the “new normal” demanded by patients and business managers. Most of the bureaucratic relationship with the patients could be digital like making a reservation for a restaurant or buying a flight ticket. Improving patient communication means higher digital adoption.

## Reporting to Patients

Reports are increasingly shared through patient portals or electronic health records (EHRs). While this improves the process, it also needs to be associated with an

improvement in the language of those reports. A high-quality radiology report is one that is not only accurate but actionable and interpretable by its end-reader. Increasingly, the readership and reach of radiology reports are expanding beyond the healthcare team to include patients and their families. We must redesign our processes and standards of communication, so they become more user-friendly to our referring clinicians and patients.

The target audience for our radiology reports now includes our patients (Lourenco and Baird 2020), provided the radiology reports can be crafted in a way that is straightforward and easy for patients to understand. It is important to proofread the text before it is validated, avoid using imaging-related jargon, skipping abbreviations, providing appropriate context and avoiding language that may be considered ‘hostile’ (or “patient-refused”). If the report can be understood by everyone, you are then adding value.

A few radiologists are proposing to share their phone numbers on the report in order to give the patient the chance to address any doubts on the report which results in better outcomes on the diagnosis and patient satisfaction (Kemp et al. 2020).



# Moving from a volume-based to a value-based practice

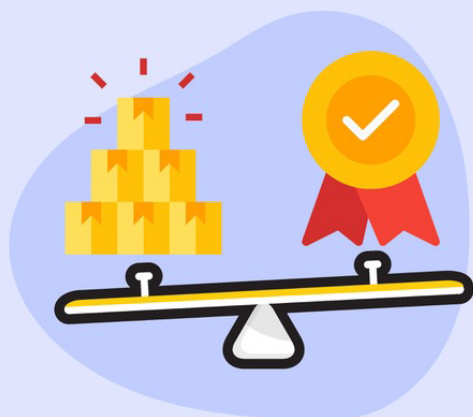


Image Credit: Paula Riera Manchón

## Moving From a Volume-Based to a Value-Based Practice

Moving into a value-driven practice requires that we work around the needs and desires of patients and referring clinicians. The principles of patient-centred care will be at the forefront of this shift. Although this transformation is intended to empower patients and improve health outcomes, it also highlights the radiologists' essential role in healthcare and makes radiologists more visible to their patients. Value sits at the centre of the discussion regarding health care redesign and patient experience is often considered a numerator in the value equation.

Nobody in radiology doubts that the incorporation of artificial intelligence is necessary to improve the radiologist's clinical role, and to help them become part of the team of professionals who interact with the patient. Anyone who thinks radiology could be a good place to avoid the patient's relationship are wrong. The clinical relevancy of the professional future of radiology makes it impossible to be hidden behind a screen. The mere image reader and report issuer is doomed to be replaced by artificial intelligence.

### We Need To Be Excellent Communicators

The product that we create in diagnostic radiology is information. It is only through information and effective communication that we affect patients' lives. In radiology, there is no doubt that communication is the cornerstone to give value to our services and humanise them.

Focusing on patient communication, we must recognise

that radiological processes were never designed to establish direct communication between radiologists and patients. Traditionally, the main role of the radiologist was to analyse the images and establish a diagnostic hypothesis and communicate it to the referring clinician. This process has traditionally excluded the patient from that communication channel.

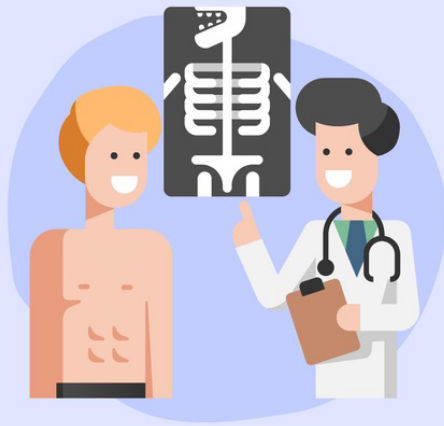
In the radiology rooms, patient images are obtained by means of technology that turns out to be strange to them, generating many uncertainties that they would like resolved as soon as possible. The radiographers face these questions every day without any training or guidelines on patients communication nor any standardisation of the information to be communicated.

Although relevant authors have for years proposed models of diagnostic communication directly with patients in patient-centred radiology proposals, it is true that it has not yet become an extended practice. The single exception could be in the breast radiology environment where radiologists have been early adopters of this practice. Communication between radiologists and patients leads to tighter bonding hence increasing patient trust in the radiology service. Patients perceive discussion with a radiologist of high value (Gutzeit et al. 2019). If your product is information, communication is your way to add value.

### Humanising Radiology

The coronavirus crisis has shown the worst part of our healthcare system. People dying alone, separated from

# Humanising radiology



**Breaking bad news**



**Communicating errors**



**Professionals Burnout**

Image Credit: Paula Riera Manchón

their families in the Intensive Care Unit (ICU) and devastated healthcare professionals has unfortunately become the image of the pandemic. From the tough lessons learned rises the necessity of redesigning our health care system into a more humanised system. Patients, families and healthcare professionals have been demanding a new model of healthcare, a human-centred care. It's time to embrace the change.

Ian Weissman, member of the American College of Radiology (ACR), has been conducting what he calls "Hello Rounds." Whenever he sees a patient on a stretcher in the hallway of the radiology department awaiting care, he stops to greet them and sees if there's anything he could do for them. It's a small step, but one that can have a profound impact on patients who might feel that they've been forgotten amidst the hustle of a busy hospital.

## Breaking Bad News

Another challenge of patient communication in radiology is breaking bad news. The radiology service generates relevant information for patients that may change the course of their lives forever. An expanding body of literature indicates that the way bad news is conveyed has meaningful consequences with respect to patient outcomes, including information recall, emotional distress, satisfaction, trust in the clinician, and treatment adherence (Porensky and Carpenter 2016).

That means we must be prepared to communicate and also give patients emotional support when we become aware of serious changes in their health. Professionals

with communication, empathy and compassion skills are the most valued by patients in these moments. Effective communication is fundamental to a successful patient-radiologist relationship; shifting the communication model to be more patient-centred has been shown to improve both quality of care and patient satisfaction (Itri 2015).

When we talk about bad news, it is important to ensure that the patient does not receive this information from a portal without proper clinical support that the situation requires. This is one of the major challenges for the digitalisation of results delivery.

## Communicating Errors

Radiology involves decision-making under conditions of uncertainty, and therefore cannot always produce infallible interpretations or reports. The interpretation of a radiologic study is not a binary process. Also, sometimes patient expectations are not close to reality. Good quality communication through education and dialogue with patients and colleagues about errors and the limitations of imaging would appear to be the only answer to misperceptions about radiological error within medicine and in the wider community (Cox and Graham 2020).

## Professional Burnout

Burnout is a global health problem affecting physicians across all medical specialties. Radiologists, in particular, experience high rates of burnout, and this trend has only continued to worsen since the COVID-19 pandemic.

Burnout refers to a constellation of symptoms, including a loss of enthusiasm for work, a high degree of emotional exhaustion, high degree of depersonalisation, and a low sense of personal accomplishment (Chetlen et al. 2019). Increasing workload is one of the leading sources of job-related stress; also repetitive tasks, complex technology environment (PACS and EHR), and feeling isolated in the reading room. The volume and complexity of information being provided to radiologists for reporting has increased enormously in recent years.

Because radiologists have limited contact with patients, radiologists are physically invisible to them, and their role as physicians also remains hidden or invisible to most patients. This lack of recognition increases the radiologists' feeling of stress.

Engagement is key when it comes to dealing with isolation. Some authors recommend that physicians work to increase their visibility and participation in providing patient care (Glazer and Ruiz-Wibbelsmann 2011). Introducing themselves to patients, explaining imaging examination procedures, creating patient-friendly imaging reports, and designing radiologic facilities that promote comfortable doctor-patient interactions is very important (Chetlen et al. 2019).

Strengthening our professional relationships and deepening our patient engagement enhances our professional

satisfaction and helps prevent burnout. Those who have experienced this believe it increases satisfaction (Kemp et al. 2020).

### Conclusion

Communication is the cornerstone of healthcare. Effective communication is not only critical to meeting patient needs and providing safe, high-quality, and patient-centred care, but it is also necessary to how we manage healthcare delivery.

The fast-changing nature of radiology means that radiologists continually have to learn and adopt new skills. Now is the time to improve communication skills in order to build the new era of radiology. Because our profession is based on service, we are already well prepared to embrace this transition. A radiologist's role extends much further than simply reporting scans and they play a central role in the management of patients. Thus, shifting to a value model care and making the radiology services a more humanised place for patients and families, and professionals is now critical for this specialty.

### Conflict of Interest

None. ■

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## Upcoming Issue

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