

# **Impacts of COVID-19 crisis on the cancer patient community**

**Insights of WECAN members on  
key patient concerns and challenges  
due to the corona crisis**

**Jan Geissler, WECAN**

**with contributions from the WECAN cancer patient community plus Tamás Bereczky and David Haerry**

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# Objectives and methods

## Objective

- ✓ Collect and map the key COVID-19 issues faced by the cancer patient community, especially in terms of
  - psychosocial and financial impact
  - patient management challenges
  - research/trial specific challenges
  - institutional challenges of patient advocacy organisations
- ✓ Identify the most important issues caused by COVID-19
- ✓ Discuss the transformational changes that may stay beyond the acute crisis
- ☐ Identify good practice examples what the patient community does to address the challenges
- ☐ Provide recommendations for patient advocacy

## Process

- ✓ Map-based collective brainstorming of pan-European patient advocacy leaders in WECAN on key factors in the four dimensions (24 WECAN advocates contributed between 18-25 May 2020)
- ✓ Rating of each of the driving factors on their impact on the patient community (13 WECAN advocates contributed to rating on 25-29 May)
- ✓ Summary of key factors (drafted by Jan Geissler, to be discussed)
- ☐ Recommendations

# **WECAN COVID-19 mapping of challenges: results**

# Collective brainstorming and prioritization: GroupMap results

## Collaborative rating (1 bar = 1 rating):

- Contributors largely agree impact
- Strong diversity of opinion



WE CAN

Psychosocial and financial impact on patients	Patient management challenges of COVID19	Trial-specific challenges of COVID19	Challenges of patient organisations due to COVID19
<p><b>STRESS AND ANXIETY OF INFECTION RISK:</b> Emotional impact (stress and anxiety) associated with fear of COVID-19 infection when going to hospital or leaving home</p> <p><b>DISTRESS ON UNCERTAINTY OF FOLLOW-UP CARE AND DISEASE PROGRESSION:</b> Emotional distress caused by uncertainty of treatment and follow up. This also causes particular strain on their families and carers.</p> <p><b>INCREASED NEED FOR PSYCHOLOGICAL COUNSELLING:</b> A lot more psychological counselling needs to be done, and capacities are lacking.</p> <p><b>ISOLATION OF THE VULNERABLE (ELDERLY, DEMENTIA):</b> People with dementia suffer from being cut off their families. They don't understand the reasons behind the ban of visitors.</p> <p><b>ISOLATION FROM FAMILY:</b> The situation of isolation and loneliness, where patients do not receive the support and encouragement from their loved ones, which is difficult to bear for many patients who are undergoing treatment</p> <p><b>PSYCHOSOCIAL FALLOUT OF SHIELDING AND CONFINEMENT:</b> Insecurity of care, insecurity of income, tensions at home - psychosocial fallout of the epidemic.</p> <p><b>CONFUSION ON DEFERRING LOCKDOWN MEASURES:</b> Differences in lifting lockdown measures between regions and countries have a potential to confuse people</p> <p><b>PRESSURE TO RETURN TO NORMALITY:</b> despite being at high risk in case of COVID infections, social pressure (not sending kids to school even if these have re-opened), return to work despite potential exposure</p> <p><b>HOME CARE CRISIS MAINLY AFFECTING WOMEN AND THEIR INCOME:</b> The (home) care crisis puts a particularly high pressure on woman, especially in poorer countries. Also in core European countries, there is a sudden lack of care personnel as people cannot travel. This also affects mostly women, who lose their income. Much of the care work is pushed out to families.</p> <p><b>INCREASED STIGMA AND DISCRIMINATION:</b> Fear of stigma and discrimination of those infected, or at risk of infection, reported from the infectious diseases area, as more parallels are drawn between the early AIDS epidemic and this one.</p> <p><b>ISSUES ACCESSING INSTITUTIONAL PATIENT SUPPORT</b> - e.g. administration issues with identifying those eligible for government support</p> <p><b>FINANCIAL VULNERABILITY:</b> Some patients are at high at risk of disease progression if infected. A different group is at high of economic impact of the crisis. Little overlap between both groups: Patients with economic vulnerabilities are people who have never felt vulnerable before.</p> <p><b>ECONOMIC IMPACT ON UNEMPLOYED AND SELF-EMPLOYED:</b> Patients who are out of work or furloughed or self-employed will be experiencing significant economic and social burden, and the 'ripple effect' will be affecting them and their families.</p>	<p><b>MOBILITY ISSUES:</b> Clinical trials tend to be conducted at large tertiary referral centers, meaning patients will often travel long distances for trials.</p> <p><b>SCREENING SUSPENDED, DELAYED DIAGNOSES:</b> Screening of breast cancers, colon cancer and cervical cancer were suspended for several months, resulting in significant diagnostic delay.</p> <p><b>POSTPONED MEDICAL CONSULTATIONS AND FOLLOW-UPS MAY CREATE MEDICAL ISSUES:</b> medical consultations not deemed to be urgent are delayed.</p> <p><b>ACCESS ISSUES TO SPECIALISED HCPs (eg oncologist):</b> Unavailability or long waiting times for consultations and appointments</p> <p><b>DELAY OF INITIAL DIAGNOSIS AND TREATMENT START:</b> Delays in diagnosis and management of newly diagnosed patients. Delays often associated with fear of people to go to hospitals.</p> <p><b>PEOPLE LIVING WITH OTHER INFECTIOUS DISEASES, SOMETIMES CHRONIC SUCH AS HIV:</b> Both our prevention and treatment delivery services were seriously impacted or collapsed.</p> <p><b>VIRTUAL CONSULTATIONS UNAVAILABLE:</b> Unavailability of virtual consultations</p> <p><b>VIRTUAL CONSULTATIONS INACCESSIBLE,</b> e.g. for elderly, less tech savvy</p> <p><b>NON-ENGLISH INFORMATION GAPS:</b> Most reliable disease-specific information is found in English, which the majority of European patients don't understand. There is a need for reliable disease-specific information in local languages.</p> <p><b>LACK OF COMMUNICATION OF CHANGED PROCEDURES:</b> Healthcare organizations must implement and communicate new procedures to keep patients safe and informed</p> <p><b>DELAY IN LAUNCH OF INNOVATIVE THERAPIES DESPITE APPROVAL:</b> For example, gene therapy for Thalassaemia has been stopped until next year even though they now have FDA approval</p> <p><b>DIFFICULTY TO DISTINGUISH COVID FROM OTHER (CANCER TREATMENT-RELATED) LUNG CONDITIONS:</b> Similarities among COVID-19, pneumonia, and oncologic treatment related effects on the lung. Patients receiving RT to the lung or mediastinum may present with overlapping symptoms of fever, cough and dyspnea with hypoxemia, that may be clinically difficult to distinguish from COVID-19.</p> <p><b>ELDERLY HOMES BECAME A DEADLY TRAP FOR MANY:</b> Lack of preparedness and resources transformed elderly homes in many countries to deadly homes.</p> <p><b>INCREASED COVID RISK:</b> Immunocompromised patients at high risk of COVID-19 infection and mortality</p> <p><b>REALLOCATION OF RESOURCES TO COVID UNITS SUSPEND CANCER SERVICES:</b> In some countries (e.g. UK), cancer wards were closed and transformed into COVID units, while cancer patients were denied continued therapy.</p> <p><b>SHORTAGE ON DRUGS, EQUIPMENT, PPE:</b> Shortage of core materials for providing sustained, safe and high quality cancer care.</p> <p><b>DELAY OF POTENTIALLY CURATIVE TREATMENT (surgery, chemo, etc)</b></p> <p><b>ICU SHORTAGE LEADING TO DEPRIORITIZED CARE OF PATIENTS WITH SERIOUS CONDITIONS:</b> Intensive care unit overload and rationing will lead to deprioritisation of patients with severe pre-conditions (e.g. cancer)</p> <p><b>COVID PATIENTS WITH CANCER MAY PUT COVID-FREE CANCER SERVICES AT RISK:</b> Hospitals have been divided in "clean" and "infected" areas. A COVID-positive cancer patient may bring infection into "clean area" of oncological services.</p> <p><b>SUPPLY SHORTAGES AND ACCESS ISSUES LIMIT MEDICAL/PALLIATIVE CARE:</b> Limitations on provision of medical and palliative care due to supply shortages and access issues</p> <p><b>LIMITS OF ICU CAPACITY IMPACT DELIVERY OF CELLULAR THERAPIES:</b> The COVID-19 pandemic has significantly impacted the delivery of cellular therapeutics, including chimeric antigen receptor (CAR) T cells. This impact has extended beyond patient care to include logistics, administration, and distribution of increasingly limited health care resources, particularly ICU capacity.</p> <p><b>CENTRALISATION OF CANCER CARE MAY CREATE MOBILITY ISSUES:</b> In some countries managers are trying to move patients to centralised hubs for cancer care, so they do not need to attend hospitals with a high risk of encountering the virus. But this is not always possible.</p> <p><b>LIMITED PUBLIC TRANSPORT CREATES MOBILITY ISSUES:</b> Limited public transport to clinics</p> <p><b>IMPACT OF SUDDEN LOCKDOWN MEASURES ON PEOPLE WITH CHRONIC CONDITIONS WHO WERE TRAVELLING:</b> People depending on medicines for a chronic condition, but got stuck by surprise due to lockdown measures. Some were stuck for weeks and months, without money, medication or health insurance coverage. Some rich countries flew people home.</p> <p><b>CROSS-BORDER CANCER CARE HALTED:</b> The closure of borders and limitations on exports and imports could threaten access to certain treatments for cancer</p>	<p><b>TRIALS CLOSING, SUSPENDED OR POSTPONED:</b> reducing treatment options and access to experimental treatments. Trial participants have to self-isolate, restricted access to clinics and hospitals, and healthcare professionals (usually involved in trials) being committed to COVID related tasks.</p> <p><b>LOST TO FOLLOW-UP:</b> With travel bans, quarantines, and stay at home orders implemented in varying degrees across the world, there are inherent limitations on patient visits for scheduled study assessments and procedures.</p> <p><b>DIRECT DELIVERY OF TRIAL DRUGS: PRIVACY ISSUES?</b> In locations where patients cannot travel to trial sites to receive delivery of investigational products (IP), direct delivery to patients has been adopted. The challenge is how to maintain patient privacy and data confidentiality?</p> <p><b>DELAYS OF TRIALS LEAD TO DELAYS OF PATIENT ACCESS:</b> Extension of trials duration, delays in reporting clinical outcomes so delays in patient access to new treatments.</p> <p><b>COVID-RELATED ADAPTATION OF TRIALS SHOULD NOT COMPROMISE TRIAL QUALITY AND SAFETY:</b> Ensure that actions to adapt ongoing trials to the situation do not compromise rights, safety and well-being of trial participants or data validity.</p> <p><b>FLEXIBILITY FOR ADAPTING TRIALS TO PRE- DURING- POST-PANDEMIC PHASES:</b> Large multicentric trials may need to adapt to different phases of the pandemic (pre-during-post-) which will differ across regions, or across countries/states within region. This may require more flexible pathway. Changes on frequency of collection of safety or efficacy endpoints</p> <p><b>CRISIS INFLUENCE ON PRO MEASUREMENTS:</b> How to differentiate impact in outcomes that may have relation with the quarantine and not with the experimental treatments, as fatigue, sleep disorders, anxiety, distress, depression, even pain that has emotional components, loss of performance status (worsening of ECOG), among others.</p> <p><b>REASSESSMENT OF RISKS IN TRIALS:</b> If COVID impacts the trial activities (or how the trial impacts the patients' risk to get other diseases, in this case COVID-19), the risks description of the trial need to be amended to incorporate the new situation, this may require new consent from patients</p> <p><b>RESOURCE SHIFT FROM CANCER RESEARCH TO PANDEMIC:</b> Sponsors and research institutions have reprioritized existing resources toward addressing the needs of the crisis</p> <p><b>WILL REDUCED FDA/EMA RULES STAY BEYOND THE PANDEMIC?</b> Both the FDA and the EMA relaxed regulations and encouraged trial sponsors to take advantage of technology (preserving patient safety). Some of these changes, may potentially make research less bureaucratic and more patient friendly, but regulatory flexibility are not intended to be kept once the COVID-19 crisis is over.</p>	<p><b>LACK OF CLINICAL GUIDANCE IN SPECIFIC CANCERS:</b> Lack of clarity and (rapidly changing) guidance on impact of COVID-19 on patients with cancer creates difficulty to provide evidence-based support to patients. Clinical guidance often appears in conflict with government guidance.</p> <p><b>NATIONAL VARIATIONS:</b> international networks struggling to tailor advice when it varies at a national level - with varying government support available and even differing clinical guidance on particular cancer type</p> <p><b>INCREASING INEQUALITIES BETWEEN HC SYSTEMS:</b> Existing weaknesses of specific health systems have been dramatically exposed</p> <p><b>HUGE INFORMATION NEEDS OF THE PUBLIC INCREASE SUPPORT DEMANDS</b> in a quickly evolving area. Not a single European country has established a COVID information hotline for the general public. Increased demand for patient support services, e.g. hotlines, emails, forum posts (despite reduced revenue). Organisations experienced an increase in calls from patients/caregivers and 40-50% of calls are COVID related</p> <p><b>PAG FUNDRAISING MASSIVELY IMPACTED, LEADING TO EXISTENTIAL FINANCIAL NGO CRISIS:</b> Existential financial crises due to COVID-related erosion of established funding and fundraising mechanisms</p> <p><b>EVIDENCING IMPACT:</b> e.g. on the organisation or patients - makes it hard for effective grant requests, letters to government, tailoring support services</p> <p><b>UNDERRESOURCING AND REDUCED CAPACITY FOR OTHER PAG SERVICES:</b> PAGs working really hard at the outset of the crisis to ensure telephone support lines could continue, but the staff are now working from home, and appropriately trained people that is usually in charge of other tasks have been moved into this role, leaving other advocacy areas behind.</p> <p><b>DEPRIORITIZATION OF NON-URGENT ACTIVITIES:</b> Postponing non-urgent or non-essential activities - but hard to consider long term impact of delaying certain activities (e.g. awareness campaigns and diagnosis)</p> <p><b>CANCELLED FACE-TO-FACE ACTIVITIES, NO EASY REPLACEMENT:</b> In-person events were core services and activities of many PAGs: patient meetings, member meetings, general assemblies, conferences</p> <p><b>STAFFING:</b> enabling working from home (equipment and workplace legislations) and reduced capacity (e.g. illness or childcare issues)</p> <p><b>TIME REQUIRED FOR COLLABORATION:</b> Trying to work together on solutions (e.g. with other PAGs) is extremely time consuming - leading to duplicated efforts or delayed responses.</p> <p><b>NEED FOR DIGITAL SKILLS:</b> Rapid need to upskill in virtual/digital technologies. Lack of expertise on digital tools and virtual meetings. Costs involved in new software and equipment.</p> <p><b>UNKNOWN IMPACT ON PAG'S STRATEGIC PLAN AND PROJECTS:</b> Challenge to understand impact on 2020 plans and deliverables. Then considering what impact this has on 2021 (e.g. fundraising ability, staffing needs)</p>

View link:

<https://join.groupmap.com/825-364-055>

# Key patient concerns and challenges caused by the COVID-19 crisis: Summary



Psychosocial and financial impact on patients	Patient management challenges
<ul style="list-style-type: none"> <li>• <b>MEDICAL:</b> Distress, anxiety, uncertainty in receiving treatment, follow-up and healthcare services; fearing risk of missed opportunities leading to disease progression</li> <li>• <b>PSYCHOLOGICAL:</b> psychological fallout of “shielding”, confinement and loneliness, burden of isolation from family members</li> <li>• <b>SOCIAL:</b> Confinement-related tensions, home care crisis; increased stigma with parallels to HIV, pressure to return back to normality (school, work) despite being at high risk on infections</li> <li>• <b>ECONOMICAL:</b> Issues accessing governmental support; new financial vulnerability; strong financial impact on unemployed and self-employed</li> </ul>	<ul style="list-style-type: none"> <li>• <b>ACCESS:</b> Suspended screening leading to delayed diagnoses; lack of access to specialized HCPs; unavailability or inaccessibility of virtual consultations, lack of knowledge about changed healthcare procedures</li> <li>• <b>CLINICAL:</b> Delayed or interrupted access to medical and palliative care; shortage on ICU, drugs and equipment, deprioritized care of patients with severe conditions (triage), risk of contamination of cancer units, delayed availability of innovative therapies (gene, cell) despite access in normal times</li> <li>• <b>INFORMATION GAPS:</b> Most reliable disease-specific COVID information available in English, which the EU patients don't understand.</li> <li>• <b>MOBILITY:</b> Centralization of specialized treatment requires travelling to remote hubs, limited public transport limits access to healthcare services, interrupted cross-border healthcare</li> </ul>
Research/trial specific challenges	Challenges of patient organisations / NGOs
<ul style="list-style-type: none"> <li>• <b>TRIAL CONDUCT:</b> Trials closing, suspended or postponed, clinical staff redirected to COVID related tasks, resource shift from cancer research to COVID research, delayed patient access to experimental treatment, extension of trial duration leading to delayed data generation and delayed regulatory submissions → patient access</li> <li>• <b>TRIAL DESIGN AND DATA:</b> adaptation of trials should not compromise patient rights, safety and well-being; flexible pathways to adapt design to pre-, during- and post-pandemic phases; does adaptation to new risk assessment require changes or re-consent of patients on trials? Crisis influence on PRO measurements</li> <li>• <b>REGULATORY:</b> Will regulatory flexibility in COVID lead to reduced bureaucracy of future post-pandemic trials?</li> </ul>	<ul style="list-style-type: none"> <li>• <b>INCREASED DEMAND FOR SUPPORT:</b> huge informational needs of patients in a quickly evolving area</li> <li>• <b>FRAGMENTED GUIDANCE:</b> varying and contradictory governmental and clinical guidance makes providing evidence-based support in specific diseases difficult; national variations are making tailored advice difficult</li> <li>• <b>ERODING RESOURCES AND ACTIVITY SHIFT:</b> Fundraising massively impacted, creating existential financial crises; resource shift to COVID support reduces capacity for other key programs, de-prioritization of non-urgent activities like diagnosis, awareness, research; cancelled face-to-face meetings without good virtual alternative leaving behind patients in need; home working reduces capacity further; digital skills needed</li> <li>• <b>UNCERTAIN STRATEGIC IMPACT:</b> Challenge to understand impact on PAG's 2020 plans and 2021 deliverables</li> </ul>



# Patient perspectives on the medical, psychological, social and emotional impact of the crisis on patients

## Patients face medical, psychological, social and emotional challenges due to the COVID-19 crisis

- **MEDICAL:** Distress, anxiety, uncertainty in receiving treatment, follow-up and healthcare services; fearing risk of missed opportunities leading to disease progression
- **PSYCHOLOGICAL:** psychological fallout of “shielding”, confinement and loneliness, burden of isolation from family members
- **SOCIAL:** Confinement-related tensions, home care crisis; increased stigma with parallels to HIV, pressure to return back to normality (school, work) for patients and partners despite being at high risk on infections
- **ECONOMICAL:** Issues accessing governmental support; new financial vulnerability; strong financial impact on unemployed and self-employed

Psychosocial and financial impact on patients	
INCREASED NEED FOR PSYCHOLOGICAL COUNSELLING: A lot more psychological counselling needs to be done, and capacities are lacking.	1
STRESS AND ANXIETY OF INFECTION RISK: Emotional impact (stress and anxiety) associated with fear of COVID-19 infection when going to hospital or leaving home.	1
DISTRESS ON UNCERTAINTY OF FOLLOW-UP CARE AND DISEASE PROGRESSION: Emotional distress caused by uncertainty of treatment and follow up. This also causes particular strain on their families and carers.	1
ISOLATION OF THE VULNERABLE (ELDERLY, DEMENTIA): People with dementia suffer from being cut off their families. They don't understand the reasons behind the ban of visitors.	1
ISOLATION FROM FAMILY: The situation of isolation and loneliness, where patients do not receive the support and encouragement from their loved ones, which is difficult to bear for many patients who are undergoing treatment.	1
PSYCHOSOCIAL FALLOUT OF SHIELDING AND CONFINEMENT: Insecurity of care, insecurity of income, tensions at home - psychosocial fallout of the epidemic.	1
CONFUSION ON DIFFERRING LOCKDOWN MEASURES: Differences in lifting lockdown measures between regions and countries have a potential to confuse people.	1
PRESSURE TO RETURN TO NORMALITY: despite being at high risk in case of COVID infections, social pressure (not sending kids to school even if these have re-opened), return to work despite potential exposure.	1
HOME CARE CRISIS MAINLY AFFECTING WOMEN AND THEIR INCOME: The (home) care crisis puts a particularly high pressure on woman, especially in poorer countries. Also in core European countries, there is a sudden lack of care personnel as people cannot travel. This also affects mostly women, who lose their income. Much of the care work is pushed out to families.	1
INCREASED STIGMA AND DISCRIMINATION: Fear of stigma and discrimination of those infected, or at risk of infection, reported from the infectious diseases area, as more parallels are drawn between the early AIDS epidemic and this one.	1
ISSUES ACCESSING INSTITUTIONAL PATIENT SUPPORT - e.g. administration issues with identifying those eligible for government support.	1
FINANCIAL VULNERABILITY: Some patients are at high at risk of disease progression if infected. A different group is at high of economic impact of the crisis. Little overlap between both groups: Patients with economic vulnerabilities are people who have never felt vulnerable before.	1
ECONOMIC IMPACT ON UNEMPLOYED AND SELF-EMPLOYED: Patients who are out of work or furloughed or self-employed will be experiencing significant economic and social burden, and the 'ripple effect' will be affecting them and their families.	1

# Patient perspectives on patient management challenges of the COVID-19 crisis

Screening, diagnosis, clinical management and follow-up of patients with cancer and other severe conditions has become specifically difficult to due to the COVID-19 crisis

- **ACCESS:** Suspended screening leading to delayed diagnoses; requirement to “shield the vulnerable”, lack of access to specialized HCPs; unavailability or inaccessibility of virtual consultations, lack of knowledge about changed healthcare procedures
- **CLINICAL:** Delayed or interrupted access to medical and palliative care; shortage on ICU, drugs and equipment leading to deprioritized care of patients with severe conditions (triage); risk of contamination of cancer units, delayed availability of innovative therapies (gene, cell) despite access in normal times
- **INFORMATION GAPS:** Most reliable disease-specific COVID information is only available in English, which most EU patients don't speak enough.
- **MOBILITY:** Centralization of specialized treatment requires travelling to remote hubs, limited public transport limits access to healthcare services, interrupted cross-border healthcare

Patient management challenges	
MOBILITY ISSUES: Clinical trials tend to be conducted at large tertiary referral centers, meaning patients will often travel to long distances for trials.	
SCREENING SUSPENDED, DELAYED DIAGNOSES: Screening of breast cancers, colon cancer and cervical cancer were suspended (e.g. in Italy for 3 months), resulting in significant diagnostic delay.	
POSTPONED MEDICAL CONSULTATIONS AND FOLLOW-UPS MAY CREATE MEDICAL ISSUES: medical consultations not deemed to be urgent are delayed.	
ACCESS ISSUES TO SPECIALISED HCPs (eg oncologist): Unavailability or long waiting times for consultations and appointments	
DELAY OF INITIAL DIAGNOSIS AND TREATMENT START: Delays in diagnosis and management of newly diagnosed patients. Delays often associated with fear of people to go to hospitals.	
PEOPLE LIVING WITH OTHER INFECTIOUS DISEASES, SOMETIMES CHRONIC SUCH AS HIV. Both our prevention and treatment delivery services were seriously impacted or collapsed.	
VIRTUAL CONSULTATIONS UNAVAILABLE: Unavailability of virtual consultations	
VIRTUAL CONSULTATIONS INACCESSIBLE, e.g. for elderly, less tech savvy	
NON-ENGLISH INFORMATION GAPS: Most reliable disease-specific information is found in English, which the majority of European patients don't understand. There is a need for reliable disease-specific information in local languages.	
LACK OF COMMUNICATION OF CHANGED PROCEDURES: Healthcare organizations must implement and communicate new procedures to keep patients safe and informed	
DELAY IN LAUNCH OF INNOVATIVE THERAPIES DESPITE APPROVAL: For example, gene therapy for Thalassaemia has been stopped until next year even though they now have FDA approval	
DIFFICULTY TO DISTINGUISH COVID FROM OTHER (CANCER TREATMENT-RELATED) LUNG CONDITIONS: Similarities among COVID-19, pneumonia, and oncologic treatment related effects on the lung. Patients receiving RT to the lung or mediastinum may present with overlapping symptoms of fever, cough and dyspnea with hypoxemia, that may be clinically difficult to distinguish from COVID-19.	
ELDERLY HOMES BECAME A DEADLY TRAP FOR MANY: Lack of preparedness and resources transformed elderly homes in many countries to deadly homes.	
INCREASED COVID RISK: Immunocompromised patients at high risk of COVID-19 infection and mortality	
REALLOCATION OF RESOURCES TO COVID UNITS SUSPEND CANCER SERVICES: In some countries (e.g. UK), cancer wards were closed and transformed into COVID units, while cancer patients were denied continued therapy.	
SHORTAGE ON DRUGS, EQUIPMENT, PPE: Shortage of core materials for providing sustained, safe and high quality cancer care.	
DELAY OF POTENTIALLY CURATIVE TREATMENT (surgery, chemo, etc)	
ICU SHORTAGE LEADING TO DEPRIORITIZED CARE OF PATIENTS WITH SERIOUS CONDITIONS: Intensive care unit overload and rationing will lead to de-prioritisation of patients with severe pre-conditions (e.g. cancer)	
COVID PATIENTS WITH CANCER MAY PUT COVID-FREE CANCER SERVICES AT RISK: Hospitals have been divided in “clean” and “infected” areas. A COVID-positive cancer patient may bring infection into “clean area” of oncological services.	
SUPPLY SHORTAGES AND ACCESS ISSUES LIMIT MEDICAL/PALLIATIVE CARE: Limitations on provision of medical and palliative care due to supply shortages and access issues	
LIMITS OF ICU CAPACITY IMPACT DELIVERY OF CELLULAR THERAPIES: The COVID-19 pandemic has significantly impacted the delivery of cellular therapeutics, including chimeric antigen receptor (CAR) T cells. This impact has extended beyond patient care to include logistics, administration, and distribution of increasingly limited health care resources, particularly ICU capacity.	
CENTRALISATION OF CANCER CARE MAY CREATE MOBILITY ISSUES: In some countries managers are trying to move patients to centralised hubs for cancer care, so they do not need to attend hospitals with a high risk of encountering the virus. But this is not always possible.	
LIMITED PUBLIC TRANSPORT CREATES MOBILITY ISSUES: Limited public transport to clinics	
IMPACT OF SUDDEN LOCKDOWN MEASURES ON PEOPLE WITH CHRONIC CONDITIONS WHO WERE TRAVELLING: People depending on medicines for a chronic condition, but got stuck by surprise due to lockdown measures. Some were stuck for weeks and months, without money, medication or health insurance coverage. Some rich countries flew people home.	
CROSS-BORDER CANCER CARE HALTED: The closure of borders and limitations on exports and imports could threaten access to certain treatments for cancer	

# Patient perspectives on the research/trial-specific challenges of the COVID-19 crisis

**Trials are suspended or postponed, trial staff is redirected to COVID-19 tasks, leading to delayed recruitment, access to experimental treatment, data generation of data, regulatory submissions, patient access**

- **TRIAL CONDUCT:** Trials closing, suspended or postponed, clinical staff redirected to COVID related tasks, resource shift from cancer research to COVID research, delayed patient access to experimental treatment, extension of trial duration leading to delayed data generation and delayed regulatory submissions & patient access
- **TRIAL DESIGN AND DATA:** adaptation of trials should not compromise patient rights, safety and well-being; flexible pathways to adapt design to pre-, during- and post-pandemic phases  
Does adaptation to new risk assessment require changes or re-consent of patients on trials? Crisis influence on PRO measurements?
- **REGULATORY:** Will regulatory flexibility in COVID lead to reduced bureaucracy of future post-pandemic trials?

Research/trial specific challenges	
TRIALS CLOSING, SUSPENDED OR POSTPONED: reducing treatment options and access to experimental treatments. Trial participants have to self-isolate, restricted access to clinics and hospitals, and healthcare professionals (usually involved in trials) being committed to COVID related tasks.	0.00 1.00 2.00 3.00 4.00 5.00 6.00 7.00 8.00 9.00 10.00
LOST TO FOLLOW-UP: With travel bans, quarantines, and stay at home orders implemented in varying degrees across the world, there are inherent limitations on patient visits for scheduled study assessments and procedures.	0.00 1.00 2.00 3.00 4.00 5.00 6.00 7.00 8.00 9.00 10.00
DIRECT DELIVERY OF TRIAL DRUGS: PRIVACY ISSUES? In locations where patients cannot travel to trial sites to receive delivery of investigational products (IP), direct delivery to patients has been adopted. The challenge is how to maintain patient privacy and data confidentiality?	0.00 1.00 2.00 3.00 4.00 5.00 6.00 7.00 8.00 9.00 10.00
DELAYS OF TRIALS LEAD TO DELAYS OF PATIENT ACCESS: Extension of trials duration, delays in reporting clinical outcomes so delays in patient access to new treatments.	0.00 1.00 2.00 3.00 4.00 5.00 6.00 7.00 8.00 9.00 10.00
COVID-RELATED ADAPTATION OF TRIALS SHOULD NOT COMPROMISE TRIAL QUALITY AND SAFETY: Ensure that actions to adapt ongoing trials to the situation do not compromise rights, safety and well-being of trial participants or data validity.	0.00 1.00 2.00 3.00 4.00 5.00 6.00 7.00 8.00 9.00 10.00
FLEXIBILITY FOR ADAPTING TRIALS TO PRE- DURING- POST-PANDEMIC PHASES: Large multicentric trials may need to adapt to different phases of the pandemic (pre-, during-, post-) which will differ across regions, or across countries/states within region. This may require more flexible pathway. Changes on frequency of collection of safety or efficacy endpoints	0.00 1.00 2.00 3.00 4.00 5.00 6.00 7.00 8.00 9.00 10.00
CRISIS INFLUENCE ON PRO MEASUREMENTS: How to differentiate impact in outcomes that may have relation with the quarantine and not with the experimental treatments, as fatigue, sleep disorders, anxiety, distress, depression, even pain that has emotional components, loss of performance status (worsening of ECOG), among others.	0.00 1.00 2.00 3.00 4.00 5.00 6.00 7.00 8.00 9.00 10.00
REASSESSMENT OF RISKS IN TRIALS: If COVID impacts the trial activities (or how the trial impacts the patients' risk to get other diseases, in this case COVID-19), the risks description of the trial need to be amended to incorporate the new situation, this may require new consent from patients	0.00 1.00 2.00 3.00 4.00 5.00 6.00 7.00 8.00 9.00 10.00
RESOURCE SHIFT FROM CANCER RESEARCH TO PANDEMIC: Sponsors and research institutions have reprioritized existing resources toward addressing the needs of the crisis	0.00 1.00 2.00 3.00 4.00 5.00 6.00 7.00 8.00 9.00 10.00
WILL REDUCED FDA/EMA RULES STAY BEYOND THE PANDEMIC? Both the FDA and the EMA relaxed regulations and encouraged trial sponsors to take advantage of technology (preserving patient safety). Some of these changes, may potentially make research less bureaucratic and more patient friendly, but regulatory flexibility are not intended to be kept once the COVID-19 crisis is over.	0.00 1.00 2.00 3.00 4.00 5.00 6.00 7.00 8.00 9.00 10.00



# Patient organization's specific COVID-19 related challenges

**Patient organisations see a surge in demand for informing patients in a quickly evolving environment while their financial base is eroding, much needed activities need to be deprioritized, and digital skills required to “move online”**

- Fundraising massively impacted, creating existential financial crises for patient organisations
- Resource shift to COVID support and home working reduces capacity for other key programs
- Cancelling face-to-face activities without a good virtual alternative leaving behind patients in need; home working reduces capacity further; digital skills are needed



LACK OF CLINICAL GUIDANCE IN SPECIFIC CANCERS: Lack of clarity and (rapidly changing) guidance on impact of COVID-19 on patients with cancer creates difficulty to provide evidence-based support to patients. Clinical guidance often appears in conflict with government guidance.	0.5	1.0
NATIONAL VARIATIONS: international networks struggling to tailor advice when it varies at a national level - with varying government support available and even differing clinical guidance on particular cancer type	0.5	1.0
INCREASING INEQUALITIES BETWEEN HC SYSTEMS: Existing weaknesses of specific health systems have been dramatically exposed	0.5	1.0
HUGE INFORMATION NEEDS OF THE PUBLIC INCREASE SUPPORT DEMANDS in a quickly evolving area. Not a single European country has established a COVID information hotline for the general public. Increased demand for patient support services, e.g. hotlines, emails, forum posts (despite reduced revenue). Organisations experienced an increase in calls from patients/caregivers and 40-50% of calls are COVID related	0.5	1.0
PAG FUNDRAISING MASSIVELY IMPACTED, LEADING TO EXISTENTIAL FINANCIAL NGO CRISIS. Existential financial crises due to COVID-related erosion of established funding and fundraising mechanisms	0.5	1.0
EVIDENCING IMPACT: e.g. on the organisation or patients - makes it hard for effective grant requests, letters to government, tailoring support services	0.5	1.0
UNDERRESOURCING AND REDUCED CAPACITY FOR OTHER PAG SERVICES: PAGs working really hard at the outset of the crisis to ensure telephone support lines could continue, but the staff are now working from home, and appropriately trained people that is usually in charge of other tasks have been moved into this role, leaving other advocacy areas behind.	0.5	1.0
DEPRIORITIZATION OF NON-URGENT ACTIVITIES: Postponing non-urgent or non-essential activities - but hard to consider long term impact of delaying certain activities (e.g. awareness campaigns and diagnosis)	0.5	1.0
CANCELLED FACE-TO-FACE ACTIVITIES, NO EASY REPLACEMENT: In-person events were core services and activities of many PAGs: patient meetings, member meetings, general assemblies, conferences	0.5	1.0
STAFFING: enabling working from home (equipment and workplace legislations) and reduced capacity (e.g. illness or childcare issues)	0.5	1.0
TIME REQUIRED FOR COLLABORATION: Trying to work together on solutions (e.g. with other PAGs) is extremely time consuming - leading to duplicated efforts or delayed responses.	0.5	1.0
NEED FOR DIGITAL SKILLS: Rapid need to upskill in virtual/digital technologies. Lack of expertise on digital tools and virtual meetings. Costs involved in new software and equipment.	0.5	1.0
UNKNOWN IMPACT ON PAG'S STRATEGIC PLAN AND PROJECTS: Challenge to understand impact on 2020 plans and deliverables. Then considering what impact this has on 2021 (e.g. fundraising ability, staffing needs)	0.5	1.0

# Patient organization's institutional COVID-19 challenges

**Patient organisations see a surge in demand for support services while their financial base is eroding. Much needed activities are deprioritized, digital skills required**

- **INCREASED DEMAND FOR SUPPORT:** huge informational needs of patients in a quickly evolving area
- **FRAGMENTED GUIDANCE:** varying/contradictory governmental and clinical guidance makes providing evidence-based support difficult
- **ERODING RESOURCES AND ACTIVITY SHIFT:** Fundraising massively impacted, creating existential financial crises.; resource shift to COVID support reduces capacity for other key programs. Deprioritization of non-urgent activities like diagnosis, awareness, research. home working reduces capacity further
- **DIGITAL SKILLS NEEDED:** Cancelling face-to-face activities leaves behind patients in need;
- **UNCERTAIN STRATEGIC IMPACT:** Challenge to understand impact on PAG's 2020 plans and 2021 deliverables

Institutional challenges of patient advocacy organisations
LACK OF CLINICAL GUIDANCE IN SPECIFIC CANCERS: Lack of clarity and (rapidly changing) guidance on impact of COVID-19 on patients with cancer creates difficulty to provide evidence-based support to patients. Clinical guidance often appears in conflict with government guidance.
NATIONAL VARIATIONS: international networks struggling to tailor advice when it varies at a national level - with varying government support available and even differing clinical guidance on particular cancer type
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PAG FUNDRAISING MASSIVELY IMPACTED, LEADING TO EXISTENTIAL FINANCIAL NGO CRISIS. Existential financial crises due to COVID-related erosion of established funding and fundraising mechanisms
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DEPRIORITIZATION OF NON-URGENT ACTIVITIES: Postponing non-urgent or non-essential activities - but hard to consider long term impact of delaying certain activities (e.g. awareness campaigns and diagnosis)
CANCELLED FACE-TO-FACE ACTIVITIES, NO EASY REPLACEMENT: In-person events were core services and activities of many PAGs: patient meetings, member meetings, general assemblies, conferences
STAFFING: enabling working from home (equipment and workplace legislations) and reduced capacity (e.g. illness or childcare issues)
TIME REQUIRED FOR COLLABORATION: Trying to work together on solutions (e.g. with other PAGs) is extremely time consuming - leading to duplicated efforts or delayed responses.
NEED FOR DIGITAL SKILLS: Rapid need to upskill in virtual/digital technologies. Lack of expertise on digital tools and virtual meetings. Costs involved in new software and equipment.
UNKNOWN IMPACT ON PAG'S STRATEGIC PLAN AND PROJECTS: Challenge to understand impact on 2020 plans and deliverables. Then considering what impact this has on 2021 (e.g. fundraising ability, staffing needs)

A hand is shown from the right side, carefully balancing a white egg on a small, dark brown wooden stand. The stand has a tiered, cylindrical shape with a small base. The background is a plain, light gray surface. The lighting is soft, casting a gentle shadow of the hand and the stand onto the surface.

# **The glass bowl: What may stay beyond the first acute COVID crisis?**

Draft interpretation by Jan Geissler,  
Tamas Bereczky, David Haerry,  
based on the WECAN survey results  
and discussions within the WECAN group

What may stay beyond the first acute COVID crisis:

## Immediate COVID-related effects like self-isolation and social distancing will stay for at least 1+ years



- Even with earliest availability, **vaccines will not be made available to everyone** for months to come, leaving many vulnerable still in 2021.
- **Self-isolation of high-risk patients will continue**, while healthier and/or vaccinated population as well as clinical practice may return to normality. Gradual relaxation of the national measures in most countries will reduce compliance with distancing and hygiene, increasing risks for the patients at high COVID-19 high risk, increasing need for self-isolation rather than them returning to near-normal social life.
- **Inequalities will increase between vulnerable and general population, as well as between richer and poorer countries.** Care crisis for elderly and frail will continue due to limited migration possibilities of professional healthcare workers.
- **With limited access to hospitals and fear of infection, (too) late diagnosis and lack of follow-up will sustain**, costing lives.
- Vulnerable patients will continue needing **virtual support, counseling and psychological support**. Clinical practice should keep **virtual counseling** and remote follow-ups as part of their standard clinical portfolio. Address issues of elderly people and patients with dementia.
- Individual's **economical fallout** will get more severe, hitting patients hardest in their inability to adapt and work
- Patient advocates supporting patients at high COVID risk need **will continue not to travel**, with sustained need to hold **virtual patient meetings, virtual ad boards, virtual conferences, virtual AGMs, virtual training**

What may stay beyond the first acute COVID crisis:

**Attention of healthcare and public funding will remain on COVID, pulling away attention from other disease areas**



- **Current downsizing of healthcare capacities will not be restored** in some countries, specifically in some CEE countries.
- Advocacy is needed, as it is **irrational to neglect research and healthcare services on the “main killers” that affect millions**, which continue to be e.g. cancer, cardiovascular, mental diseases, ageing population, while pandemic research is continuing
- **Safeguard civil liberties** in a world where contact tracing will be de rigueur in coming years



What may stay beyond the first acute COVID crisis:

**Patient organisations, with other stakeholders, must address healthcare inequalities, and support self-isolating high-risk population**


- Focus on **alternatives to in-person events and meetings**
- Find solutions for **elderly people** where digital tools won't be applicable.
- **Deliver tailored support** to a vulnerable population in high demand, based on most up to date evidence
- Secure **sustainable funding** for patient orgs to address resource gaps



# **Patient advocacy activities to address the COVID-19 challenges**

Examples from the WECAN members

## WECAN member resources on COVID-19



**COVID-19 Resources of WECAN members**

The Corona virus and the COVID-19 epidemic is of concern to many cancer patients who are in special need of cancer treatment and follow-up care which may have become inaccessible, and may not get access to appropriate care in case of a COVID-19 infection.

The situation, individual risks and informational needs however differ from cancer to cancer and from country to country.


Many WECAN member organizations are providing informational resources about COVID-19 and about specific recommendations to their patient community. Here you find links to the COVID-19 resources provided on the websites of those patient organizations, which may link to additional relevant articles and tools for their specific disease area.

Cancer type	COVID-19 website of the WECAN member
Brain tumours	<b>International Brain Tumour Alliance (IBTA)</b> COVID-19 information for the international brain tumour community. <a href="#">Link</a>
Childhood cancers	<b>Childhood Cancer International</b> COVID-19 information for patients, families and survivors. <a href="#">Link</a>
Chronic Lymphocytic Leukemia (CLL)	<b>CLL Advocates Network</b> COVID-19 statement. <a href="#">Link</a>
Chronic Myeloid Leukemia (CML)	<b>CML Advocates Network</b> CML and COVID-19 Recommendations, News, Media, Scientific Literature, Telegram Channel. <a href="#">Link</a>
Digestive Cancers (Colorectal, Gastric, Pancreatic)	<b>Digestive Cancers Europe (DCE)</b> COVID-19 Series: How our Members are Helping Patients through the Novel Coronavirus COVID-19 Pandemic. <a href="#">Link</a> About Digestive Cancers and the Coronavirus. <a href="#">Link</a>
Lung cancer	<b>Lung Cancer Europe (LCE)</b> COVID-19: Corona Virus and Lung Cancer. <a href="#">Link</a>
Lymphoma	<b>Lymphoma Coalition</b> COVID-19: Advice for patient groups from haemoball in China. <a href="#">Link</a>
Melanoma	<b>Melanoma Patients Network Europe (MPNE)</b> Continuous update on all COVID-19 and cancer, plus specific melanoma guidelines. <a href="#">Link</a>
Multiple myeloma	<b>Myeloma Patients Europe (MPE)</b> Publications, tips for patients, global information, national information. <a href="#">Link</a>
Myelodysplastic Syndrome (MDS)	<b>International MDS Alliance</b> Recommendations and resources for members and patients. <a href="#">Link</a> Link to blood donation appeal. <a href="#">Link</a>
Neuroendocrine Cancers	<b>International Neuroendocrine Cancer Alliance</b> Information Resource for Neuroendocrine Cancer Patients. <a href="#">Link</a>
Sarcomas	<b>Sarcoma Patients Europe (SPE)</b> Resources about the coronavirus in general and especially for cancer patients, including specific information for sarcoma and GIST patients. <a href="#">Link</a>

Other helpful resources specific to cancer and COVID-19

There is a huge amount of scientific and non-scientific resources and articles on COVID-19. This page does not intend to list them all or to be complete. It aims to provide links to the COVID-19 specific pages of European cancer patient umbrella organisations as well as to resources applicable to COVID-19 issues in oncology.

## WECAN Virtual Meetings Resource Center



### Virtual Meetings Resource Center

By providing this WECAN Virtual Meeting Resource Center, we support the patient advocacy community through providing knowledge, guidance and checklists for patient organizations to run virtual meetings. [More about the project here.](#)

**Checklists for the implementation of different types of meetings**

- Online lectures and webinars
- Virtual collaborative working group meetings
- Virtual General Assemblies and Elections

**Planning the agenda, content and moderation**

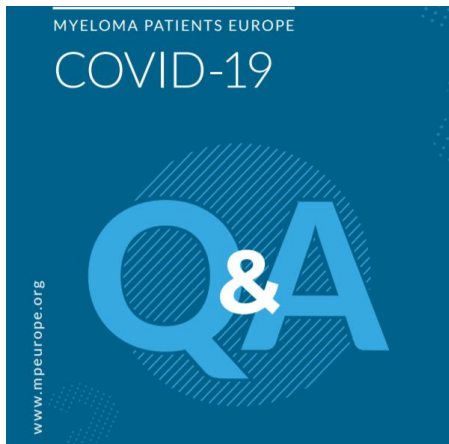
- Booking agendas and moderator training
- Guide for your meeting participants
- Preparing your participation in the virtual meeting using Zoom
- Inviting participants and setting access restrictions
- Drafting your speeches and reviewing presentations
- Room to come! Managing and moderating virtual meetings

**Setting up virtual meetings**

- Choosing and setting up your online meeting platform
  - Comparison of online meeting platforms (Zoom, Teams, WebEx, GoToMeeting, Skype for Business)
  - Webinar or video conference package? Which option is right for my meeting?
- Setting up Zoom meetings
- Setting up GoToMeeting meetings
- Guide for your meeting participants
- Preparing your participation in the virtual meeting
- Online collaboration and interaction tools
  - Using a waiting or secure entry system
  - Room to come! Online interaction and collaboration tools
- Specific webinar/presentation related services
- Room to come! Recording, broadcasting, making webinars available for streaming, analytics
- Room to come! Soon to come: Storing meeting content in the cloud



## COVID-19 Outreach: Videos, Telegram channel, Q&A with HCPs, translated info



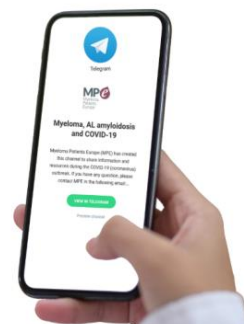
MYELOMA PATIENTS EUROPE

# COVID-19

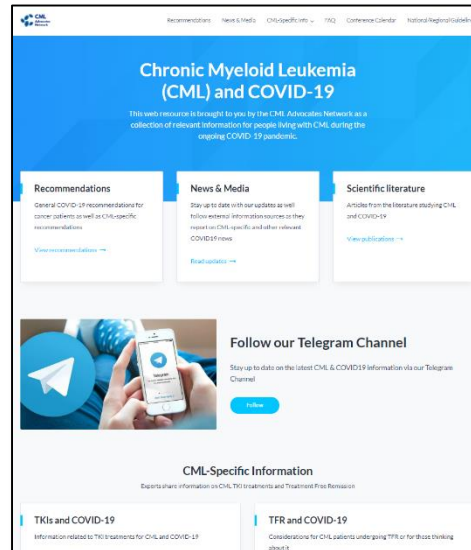
# Q&A

[www.mpeurope.org](http://www.mpeurope.org)

MPE Telegram channel on COVID-19



## Facebook Live, Webinars, Telegram Channel, COVID-19 science, CML COVID-19 case collection



**Chronic Myeloid Leukemia (CML) and COVID-19**

This web resource is brought to you by the CML Advocates Network as a collection of relevant information for people living with CML during the ongoing COVID-19 pandemic.

**Recommendations**  
General COVID-19 recommendations for cancer patients as well as CML-specific recommendations. [View recommendations](#)

**News & Media**  
Stay up to date with our updates as well follow external information sources or they report on CML-specific and other relevant COVID-19 news. [Find updates](#)

**Scientific literature**  
Articles from the literature studying CML and COVID-19. [View publications](#)

**Follow our Telegram Channel**  
Stay up to date on the latest CML & COVID-19 information via our Telegram Channel. [Follow](#)

**CML-Specific Information**  
Experts share information on CML, TKI treatments and Treatment-Free Remission

**TKIs and COVID-19**  
Information related to TKI treatments for CML and COVID-19

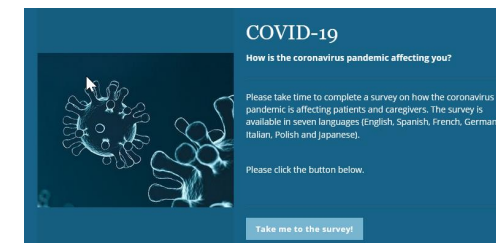
**TFR and COVID-19**  
Considerations for CML patients undergoing TFR or for those thinking about it



## International Brain Tumor Alliance



2 surveys of 1989 patients and caregivers and 77 brain tumor charities to identify areas of greatest need during pandemic



**COVID-19**

How is the coronavirus pandemic affecting you?


Please take time to complete a survey on how the coronavirus pandemic is affecting patients and caregivers. The survey is available in seven languages (English, Spanish, French, German, Italian, Polish and Japanese).

Please click the button below.

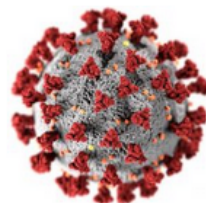
[Take me to the survey](#)

# COVID-19 resources of WECAN members

- Many WECAN member organisations are providing informational resources about COVID-19 and about specific recommendations to their patient community.
- On [www.wecanadvocate.eu/covid-19](http://www.wecanadvocate.eu/covid-19), you find links to the COVID-19 resources provided on the websites of those patient organisations, which may link to additional relevant articles and tools for their specific disease area
- Launched in March 2020, regularly updated



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### COVID-19 Resources of WECAN members

The Corona virus and the COVID-19 epidemic is of concern to many cancer patients who are in special need of cancer treatment and follow-up care which may have become inaccessible, and may not get access to appropriate care in case of a COVID-19 infection.

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Other helpful resources specific to cancer and COVID-19

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Good practice example:

# WECAN Virtual Meetings Resource Center



## Organisation

WECAN (Workgroup of European Cancer Patient Advocacy Networks)

## Objective

Enable the cancer patient community to switch to virtual meetings as they struggle to hold face-to-face meetings, general assemblies and workshops during the pandemic: Training the community on holding webinars, workgroup meetings and AGMs online professionally

## Activity

Open-access toolbox for patient organisations to facilitate holding virtual meetings

- Checklists
- Setting up online meetings (Zoom, GoToMeeting)
- Security settings
- Guides for your participants (headsets, cameras, online interaction)
- Online voting

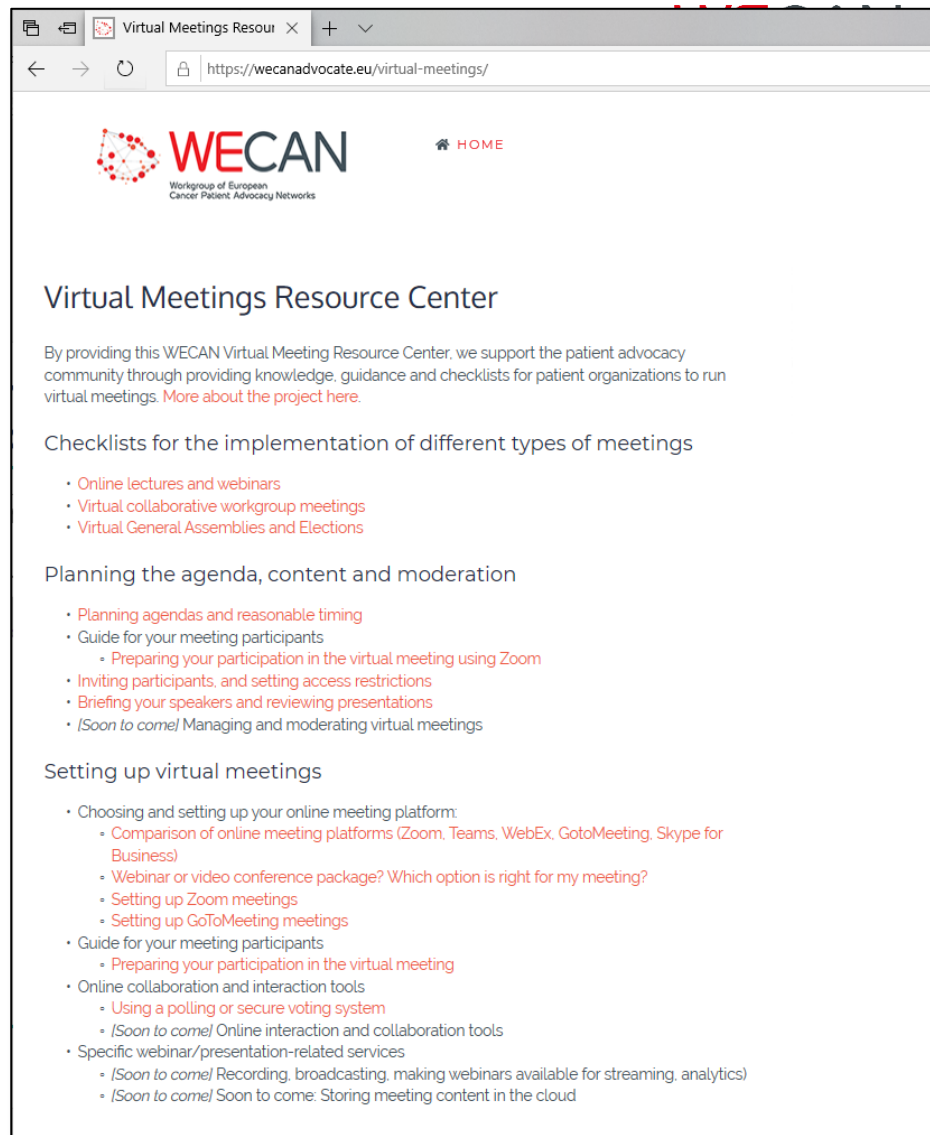
Not cancer specific! Released under Creative Commons License for everyone to reuse.

## Timeline

Launch on 11 June 2020, more updates and extensions to come

## Links

[www.wecanadvocate.eu/virtual-meetings](https://www.wecanadvocate.eu/virtual-meetings)





# Good practice example: MPE COVID-19 Outreach Workstream

## Organisation

Myeloma Patients Europe

## Objective

- To develop a suite of educational resources specifically to inform and support our members, and myeloma and AL amyloidosis patients across Europe during the COVID-19 pandemic
- To create a comprehensive social media plan, targeted to our audience and with maximum-impact messages in order to support members and patients during the pandemic through easily accessible and relevant information
- To support our members in continuing their mission locally supporting patients and carers through supply of tailored resources and support in order to promote resilience and sustainability of their organisations

## Activity

Activity so far has included:

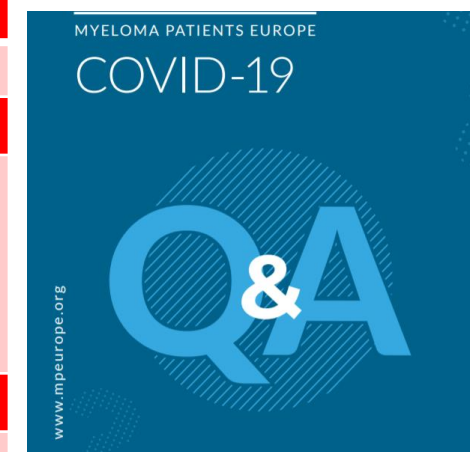
- Member needs assessment to assess organizational need, impact on members and patients/carers at a local level, and plan for next phase of support to members
- Suite of videos presented by specialists aimed to promote health, wellbeing, and also address psychosocial aspects of confinement
- Creation of a dedicated Telegram channel for members, patients and carers broadcasting relevant information
- Social media plan to support dissemination of relevant news, information and updates
- A Q&A with doctors and specialists around access to treatment, trials and other relevant information for patients and carers in addition to other resources
- Translation of all materials into local languages to ensure these are accessible for patients / carers across Europe

## Timeline

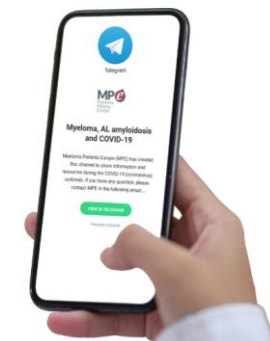
The workstream launched in early March 2020. Educational resources including videos, website, Telegram and social media output will continue in line with identified priorities and needs of members, and to provide updates and education throughout the programme. Report on Member needs assessment to be published July 2020. MPE COVID-19 Scholarship will be available for application from mid-August 2020.

## Links

<https://www.mpeurope.org/covid-19/>



MPE Telegram channel  
on COVID-19



Good practice example:

# CML Advocates Network: COVID-19 educational activities

## Organisation

CML Advocates Network

## Objective

- Support information needs of our global community of patient advocates by centralizing key CML/COVID-19 information (Scientific, Public-Health, Best-Practises, News) via an online resource hub
- Provide assistance and training to CML patient advocacy community to develop skillset to attend virtual congresses
- Collaborate with wider CML community to collect information from the patient community

## Activity

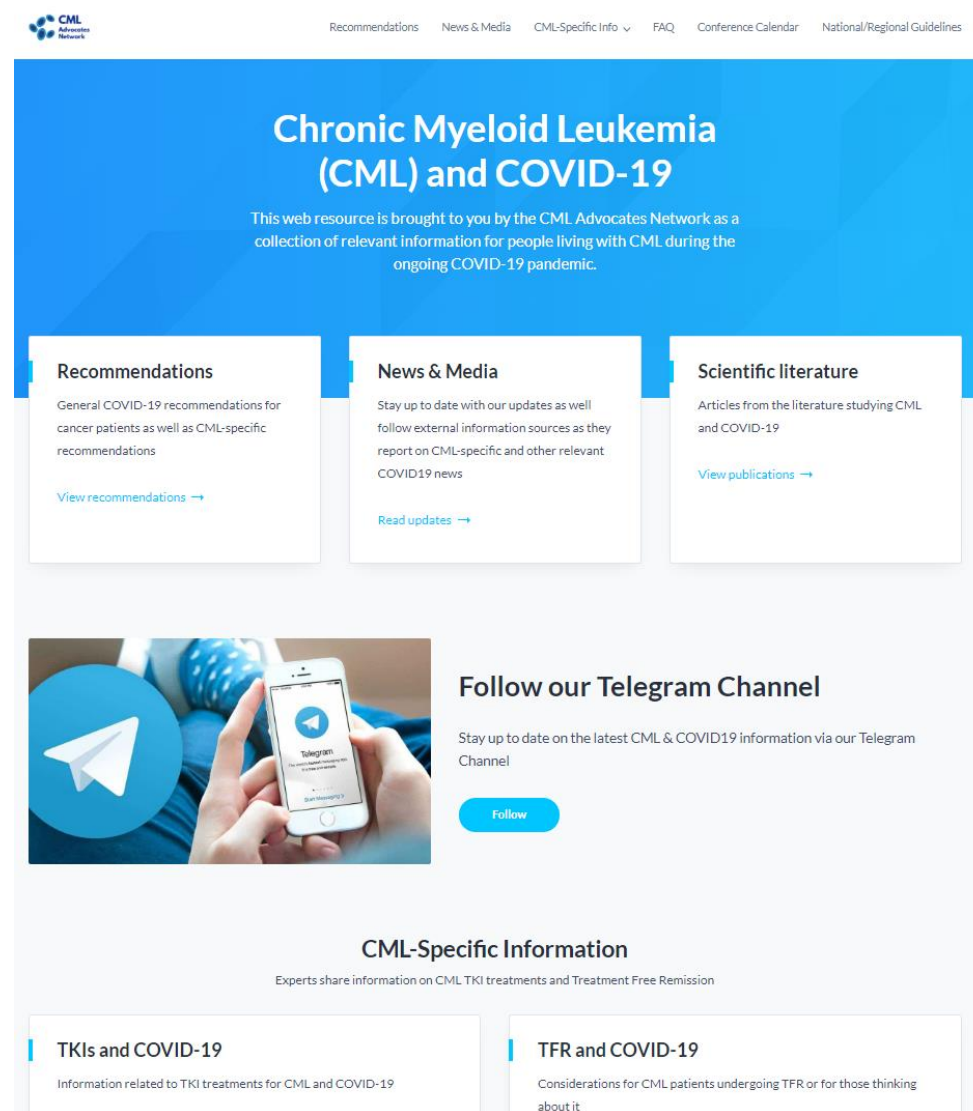
- Setup a Telegram channel to share latest information added to the online resource hub: <https://t.me/cmlan>
- Developed guidance and webinar content (Facebook Live) to make most of attending major congresses
- Develop comprehensive COVID-related social media plan and newsletter series.
- Collaboration with international clinical network iCMLF in order to provide patient community input into identifying cases of CML patients diagnosed with COVID-19

## Timeline

Launch on 17 April 2020 with continuous updates

## Links

<https://covid19.cmladvocates.net/>



The screenshot displays the CML Advocates Network website. At the top, the navigation bar includes links for Recommendations, News & Media, CML-Specific Info, FAQ, Conference Calendar, and National/Regional Guidelines. The main header features the CML Advocates Network logo and the title "Chronic Myeloid Leukemia (CML) and COVID-19". Below the header, a sub-header states: "This web resource is brought to you by the CML Advocates Network as a collection of relevant information for people living with CML during the ongoing COVID-19 pandemic." The content is organized into three columns: "Recommendations" (General COVID-19 recommendations for cancer patients as well as CML-specific recommendations, with a "View recommendations" link), "News & Media" (Stay up to date with our updates as well follow external information sources as they report on CML-specific and other relevant COVID19 news, with a "Read updates" link), and "Scientific literature" (Articles from the literature studying CML and COVID-19, with a "View publications" link). Below these columns, there is a section titled "Follow our Telegram Channel" with a Telegram logo and a "Follow" button. The bottom section is titled "CML-Specific Information" and includes two sub-sections: "TKIs and COVID-19" (Information related to TKI treatments for CML and COVID-19) and "TFR and COVID-19" (Considerations for CML patients undergoing TFR or for those thinking about it).

Good practice example:

# International Brain Tumor Alliance Survey on COVID-19 impact



## Organisation

International Brain Tumor Alliance

## Objective

Capture the concerns and challenges of adults, children and caregivers affected by brain tumours during the difficult pandemic. Generate data to identify where there is greatest need. Share results with non-profit organisations around the world that are caring and supporting brain tumour patients.

## Activity

Two surveys conducted:

- (1) COVID-19 and the brain tumour patient and caregiver experience. 1989 patients and caregivers from 33 countries responded
- (2) COVID-19: the brain tumour charity and not-for-profit experience: 77 brain tumour patient organisations from 22 countries.

The data is currently being analysed and written up for publication. Lay versions of the data will also be provided.

## Timeline

Survey run April – May 2020.

## Links

<https://theibta.org>



Good practice example:  
**[insert title of activity here]**

**TEMPLATE**

### Organisation

[your organization's name]

### Objective

[describe the objectives of activity]

### Activity

[describe the activity here]

### Timeline

[when did it start and when are major milestones?]

### Links

[link to your page with more info]

Add a screenshot or  
illustration or logo  
here