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

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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

- Contributors largely agree impact
- Strong diversity of opinion

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

- **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) despite being at high risk on infections
- **ECONOMICAL:** Issues accessing governmental support; new financial vulnerability; strong financial impact on unemployed and self-employed

#### Patient management challenges

- **ACCESS:** 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
- **CLINICAL:** 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
- **INFORMATION GAPS:** Most reliable disease-specific COVID information available in English, which the EU patients don’t understand.

#### Research/trial specific challenges

- **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?

#### Challenges of patient organisations / NGOs

- **INCREASED DEMAND FOR SUPPORT:** huge informational needs of patients in a quickly evolving area
- **FRAGMENTS GUIDANCE:** varying and contradictory governmental and clinical guidance makes providing evidence-based support in specific diseases difficult; national variations are making tailored advice difficult
- **ERODING RESOURCES AND ACTIVITY SHIFT:** 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
- **UNCERTAIN STRATEGIC IMPACT:** Challenge to understand impact on PAG’s 2020 plans and 2021 deliverables
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

Source: WECAN Members, Patvocates Team

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**Psycosocial and financial impact on patients**

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Source: WECAN Members, Patvocates Team
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 accessibility 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.

Source: WECAN Members, Patvocates Team
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?
Patient organisation’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

Source: WECAN Members, Patvocates Team
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

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**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 guidelines.
- **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.
- **INCREASING INEQUALITIES BETWEEN IC SYSTEMS:** Existing weaknesses of specific health systems have been dramatically exposed.
- **HUGE INFORMATION NEEDS:** 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. helplines, emails, forum posts under renewed pressure. Organisations experienced an increase in calls from patients/caregivers and 40-50% of calls are COVID related.
- **FAG FUNDRAISING MASSIVELY IMPACTED:** Leading to existential financial NGO crisis. Existential financial crisis due to COVID-related cessation of established funding and fundraising mechanisms.
- **EVIDENCE INEFFECTIVE:** e.g. on the organisation or patient - makes it hard for effective grant requests, letters to government, tailoring support services.
- **UNEMPLOYMENT AND REDUCED CAPACITY:** Often PAG's services. PAGs are now hard at the tasks of the crisis to ensure support; support has continued, but the staff are now working from home, and appropriately trained people who is usually in charge of other tasks have been moved into this role, leaving other advocacy areas behind.
- **DISPROPORTION OF NON-URGENT ACTIVITIES:** Reducing non-urgent or non-essential activities such as travel to congresses and meetings, etc.; vital work has been scaled back, leaving other advocacy areas behind.
- **CANCELLATION OF FACE-TO-FACE ACTIVITIES:** Not easy replacement. Important events were core services and activities of many PAGs; patient meetings, general assemblies conferences.
- **STAFFING:** enabling working from home (equipment and workspace legislation) and reduced capacity (e.g. illness or childcare issues).
- **TIME REQUIRED FOR COLLABORATION:** Depending on the cooperation on solutions (.e.g. with other organisations) to collaborate on solutions, leading to drafting of work on delay response.
- **NEED FOR DIGITAL SKILLS:** Rapid needs upskill in digital technologies. Lack of expertise in digital tools and virtual meetings. Costs involved in new software and equipment.
- **UNKNOWN IMPACT:** Divides strategic plan and projects. Challenge to understand impact on 2020 plans and deliverables. Then considering what impact that has on 2021 (e.g. fundingarity, staffing needs).

Source: WECAN Members, Patvocates Team
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

WECAN Virtual Meetings Resource Center

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

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

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 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, 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
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
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/
**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/
Good practice example:
**International Brain Tumor Alliance Survey on COVID-19 impact**

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<thead>
<tr>
<th>Organisation</th>
<th>International Brain Tumor Alliance</th>
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<tbody>
<tr>
<td><strong>Objective</strong></td>
<td>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.</td>
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<tr>
<td><strong>Activity</strong></td>
<td>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.</td>
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<td><strong>Timeline</strong></td>
<td>Survey run April – May 2020.</td>
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Good practice example: [insert title of activity here]