



Outcomes report

Patient insights for sustainable care – improving efficiency in care for all

European Health Forum Gastein | Thursday 4 October 2018

1. Overview

At the 21st European Health Forum Gastein (EHFG), the international All.Can initiative hosted a session entitled 'Patient insights for sustainable care – improving efficiency in care for all', in which stakeholders were invited to suggest policy changes and real-world solutions to tackle the issues identified in the global All.Can patient survey. The All.Can patient survey was launched in early 2018 to gain patients' insights into where they had encountered inefficiencies in their cancer care, to inform All.Can on where policy changes should be made.

Lieve Wierinck MEP, a member of both All.Can and the MEPs Against Cancer group (MAC), proudly gave a keynote introduction for the session via video to highlight the need to improve efficiency, share learning and benchmark best practice across Europe. Kathy Oliver, All.Can member and co-founder of the International Brain Tumour Alliance, moderated the session.

The theme of this year's EHFG was 'Bolder political choices to achieve the Sustainable Development Goals', making it the perfect opportunity to look at the issues identified in the survey and advocate for policy changes to improve the future of cancer care. The hope is that this model for patient-driven policy change can be transferred to other disease areas.

2. Emerging themes from the patient survey

Daniel Ratchford of Quality Health, the organisation running the All.Can patient survey, discussed the dissemination of the survey and presented the core themes emerging from the interim results, as well as highlighting the importance of listening to patients' voices when it comes to decision-making. With the survey nearing its deadline, Daniel was able to offer a comprehensive overview of recurring issues found in the survey results.

Attendees were presented with four themes and several patient quotes, to understand the substantial distress that inefficiencies can cause patients. Daniel noted that treatment was not mentioned in the top-four issues listed – it was often other areas of the patient pathway that had the most significant negative impact on quality of life.



The session focused on four emerging themes:

1. **Diagnosis:** for many patients, their cancer was diagnosed as something different, either once or several times.
2. **Lack of psychological support:** respondents said they needed psychological support throughout their cancer care, and this was often either inadequate or unavailable.
3. **Time and timing:** many respondents said that hospitals/clinics had cancelled appointments at least once.
4. **Financial toxicity:** differences in policy and health insurance mean that cancer patients often pay for varying amounts of their care and treatment in different healthcare systems, causing significant financial difficulty and distress to families.

The survey contains a mix of open-ended and multiple-choice questions and covers the entire care pathway. Daniel noted the importance of open-ended questions in the survey, stating: 'It's often in the qualitative data where the deepest insights lie.' Attendees were shown a breakdown of where patients identified inefficiencies across three countries; while there were many similarities, there were also country-specific areas highlighted.

3. The workshop and reporting back

After the presentation of interim findings, the session attendees began a workshop to look at the core themes emerging from the All.Can patient survey in more depth, and come up with policy solutions.

Each table of attendees was given a theme and corresponding quote to work with. The quotes were from real patients who had responded to the survey. Each table was asked to develop political and practical solutions in relation to their theme and quote. With a diverse range of stakeholders and representatives from numerous organisations present, we were delighted to hear the detailed and thought-provoking conversations taking place.

Following the workshop, each group presented a two-minute 'elevator pitch' based on the suggestions from their group discussions, aimed at policymakers or key decision-makers. There were several excellent suggestions with compelling arguments as to why policy changes are needed at both a European and national level.



Some of the suggestions put forward included:

Diagnosis

- Leverage communication and digital channels to reduce patient anxiety.
- Use data to create risk profiles to help clinicians predict future issues.
- Enable healthcare professionals and social workers to communicate diagnosis and healthcare concerns.
- Highlight the economic benefits of improving diagnosis.

Lack of psychological support

- Map mental health and oncology legislation to see where gaps exist in care across countries.
- Ensure teams are working efficiently together as a multidisciplinary team.
- Develop a strategic plan at both national and EU level for integrated cancer and psychological support.
- Give each patient and family a dedicated counsellor to guide them through their care.
- Integrate psychological and social skills in the medical curriculum.
- Develop a European strategy for integrated health and social care.

Time and timing

- Break down financial silos, and create digital tools for patients and multidisciplinary teams to ensure patients receive results as soon as they become available.
- Create EU benchmarks to monitor and manage waiting times.
- Incorporate digital solutions for integrated care into EU digital policy.
- Invest in the healthcare workforce to prevent further shortages.
- Measure processes and infrastructure to highlight bottlenecks.
- Speed-up referral processes and ensure patients receive the right treatment at the right time.

Financial toxicity

- Adopt a holistic approach to ensure patients are not required to pay for numerous aspects of their cancer care experience (e.g. parking or transport to hospital appointments, psychological and other treatments etc).
- Reimburse patients or provide finance in advance.
- Create better coordination along the cancer care pathway.
- Exchange best-practice examples among EU member states to learn where patients need financial support.



4. Panel discussion

Following the group presentations, the panel was given the opportunity to respond to the ideas from the room, and give their thoughts on the themes based on personal insights and expertise. The panel consisted of: Stefan Gijssels from EuropaColon, Yolande Lievens from the European CanCER Organisation (ECCO) and European Society for Radiotherapy and Oncology (ESTRO), Dirk Van den Steen from DG SANTE of the European Commission, Zeger Vercooteren from Johnson & Johnson and Xavier Franz from Varian Medical Systems.

Speaking about the European institutions' role in improving efficiency in cancer care, Dirk Van den Steen said: 'If we look at benchmarks for efficiency at the EU level, we do have benchmarks but they're not very granular. These [areas of inefficiency identified by patients in the survey] are certainly areas that can be picked up – it's been done before. It's also important to identify, scale-up and transfer best practices.'

Referring to transparency in reporting patient outcomes across hospitals in Europe, Stefan Gijssels said: 'Having transparency for hospital outcomes and overall survival would be fantastic because it would push hospitals to improve their practices, it will guide patients [on] where to go with a specific disease, and they can learn from those with the best overall survival rates.'

Yolande Lievens gave her perspective as a radiotherapist: 'Quality personalised care is certainly something that we support very heavily. Having the optimal treatments available is extremely important: you can have the best treatment, but if every patient doesn't get the same approach, we are wasting our energy.'

Representing the pharmaceutical industry, Zeger Vercooteren commented on the importance of working together to solve the multi-faceted problems identified by patients: 'In order to take on and address these challenges... we need a holistic approach.'

Xavier Franz also commented on the need for a unified approach, adding: 'The holistic approach is extremely important. We are all extremely connected, except in health where we are extremely behind. This is something that needs to be taken into account at the EU and national level.'



5. What's next?

All.Can will be taking the thoughts and recommendations suggested by the audience and the panel, and integrating them into our policy implementation phase of work in 2019 and beyond.

All.Can will publish the results from the patient survey in early 2019. With many questions still to be answered, we will continue to look at the issues raised by patients and see how insights from the survey, and discussions from the EHFG session, can help drive better cancer care for patients in the future.

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