

Evidence-informed policy to tackle childhood cancer in Uzbekistan

A narrative case study



Keywords

EVIDENCE-INFORMED HEALTH POLICY KNOWLEDGE
TRANSLATION
HEALTH POLICY MAKING
RESEARCH USE IN POLICY MAKING
CHILDHOOD CANCER
UZBEKISTAN

Document number:
WHO/EURO:2022-5884-45649-65537

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Acknowledgements

Many thanks to everyone who agreed to be interviewed for this case study: Indira Erimbetova, Sapura Ibragimova, Eldor Iskhakov, Nazokat Kazymova, Munira Khodjakhanova, Nigora Muratova and Vitaly Smelov.

Thanks also to Ulugbek Abdugaffarov, who acted as interpreter, Marilys Corbex, who led the collaboration from the WHO Regional Office for Europe cancer control team side and everyone involved in making this project happen.

This case study was conceived by Marge Reinap and researched and written by Polly Mitchell. Funding was provided by the Health Policy Development and Implementation Unit at WHO Regional Office for Europe, the Wellcome Trust [22 1503/Z/20/Z] and the German Government.



This case study describes a project in Uzbekistan, supported by the WHO Evidence-informed Policy Network (EVIPNet), to develop evidence-informed policy to prevent and manage childhood cancer. In an exceptional example of impactful bottom-up policy-making, clinicians, researchers and policy-makers developed an evidence-informed report that put childhood cancer on the national agenda, secured the support of the President of the Republic of Uzbekistan and led to the development of policies that are expected to improve outcomes for children with cancer. Working to build health policies from the ground up has transformative power: it can build capacity, change perceptions and garner support for better policy-making across the whole system.

Key messages

- Evidence-informed policy-making can produce big improvements in health outcomes.
- WHO EVIPNet delivers hands-on, tailored training in evidence-informed policy-making.
- In Uzbekistan, training professionals in evidence-informed policy-making led to timely, appropriate childhood cancer policy action to tackle poor practices and outcomes.
- The training programme helped to build capacity and increase government support for future evidence-informed policy-making.

Childhood cancer in Uzbekistan

Outcomes for children with cancer in Uzbekistan are poor, but evidence-informed treatment protocols and strategies have the potential to generate substantial improvements.

Children with cancer in Uzbekistan have a survival rate of only 30–40%.¹ This represents many avoidable deaths: survival rates of over 80% are now achievable in higher-income countries (1). There is also unequal access to diagnosis and treatments both within and across regions in Uzbekistan, leading to variable outcomes across the country. Overall, fewer than half the expected cases of the most common paediatric cancers are diagnosed (2). Delayed diagnosis and treatment increase disease burden and deaths, cause financial and emotional strain for families, and generate health system pressures. In Uzbekistan children with cancer have no access to adequate palliative care. Mainly due to structural barriers such as lack of home-based health-care services and specialists, but also because of fears and misconceptions (3).

Childhood cancer was an area which really needed some support – particularly in relation to policy development and evidence-informed policy development.

**Nazokat Kasymova, National Professional Officer,
WHO Country Office in Uzbekistan**

There is much that can be done to improve treatment and outcomes. The use of evidence-informed strategies can prevent 30–50% of cancers, and evidence-informed diagnostic tools and treatments can significantly reduce disease burden and deaths (4). In Uzbekistan, the five-year survival rate for acute lymphoblastic leukaemia – a severe form of blood and bone marrow cancer – in children is now around 75% due to the introduction of the Moscow–Berlin treatment protocol, which combines chemotherapy and immunotherapy. However, the survival rate is just 30% for those with solid tumours and lymphomas, which are not treated with an updated protocol.

Uzbekistan has been selected as one of 10 focus countries for WHO's Global Initiative for Childhood Cancer. The initiative aims to achieve 60% survival for children with cancer worldwide by 2030, preventing 1 million deaths (1). In early 2020 a Childhood Cancer Working Group was established by the Ministry of Health in Uzbekistan to develop an action plan. This posed a unique opportunity to accelerate progress towards improved care and outcomes.

¹ Unless otherwise cited, facts and figures in this section are taken from the evidence-informed explanatory note Tackling Childhood Cancer Prevention and Control in Uzbekistan, which is the subject of this case study.

Evidence-informed policy-making webinars and training

Box 1. What is evidence-informed policy?

Getting evidence into policy-making. Health policies that are grounded in evidence-supported solutions are the most likely to improve health outcomes. However, getting high-quality research evidence into policy is not easy. Sometimes policy decisions are made for political or partisan reasons, and research is not valued by policy-makers. At other times, research is of low quality, irrelevant or not available when policy-makers need it. Limited communication channels between researchers and policy-makers can prevent needs and knowledge from being shared.

Knowledge translation. Specific knowledge translation tools can help to ensure that relevant, high-quality evidence reaches policy-makers at the right time to help them to make better policy decisions. Contextual and political factors will always play a role in policy-making – and this is not a bad thing – but knowledge translation efforts can help to ensure that policies are also based on evidence.

Evidence briefs for policy. An evidence brief is a knowledge translation tool that summarizes the best available evidence about a policy issue and the most promising solutions to it, tailored to a particular social and political context.

WHO organized a webinar series on evidence-informed policy-making, which helped country teams to develop evidence-informed policy reports.

In the autumn of 2020, WHO EVIPNet Europe and the WHO Country Office in Uzbekistan hosted a series of practical webinars to train policy-makers, researchers and clinicians in central Asia and eastern Europe in evidence-informed policy-making. In a spirit of “learning by doing”, WHO supported participating teams from Georgia, Kyrgyzstan, Turkmenistan and Uzbekistan to develop an evidence brief for policy to support policy-makers in their country in tackling a high-priority health issue.

The month-long training comprised an introductory session and five webinars, which covered the principles of evidence-informed policy-making across the policy cycle. Sessions on the development of evidence briefs for policy focused on

- identifying and framing a policy problem
- accessing and evaluating evidence
- generating appropriate policy solutions
- identifying barriers to implementation.

There was also a session on conducting policy dialogues and supporting the uptake of policy briefs. A productive and supportive learning environment was created using a plenary discussion, hands-on sessions, tailored resources, real-time individualized feedback from WHO staff and an experienced facilitator from the Knowledge to Policy Center at the American University of Beirut, in Lebanon, plus plenty of time to consolidate and apply knowledge.

The Childhood Cancer Working Group in Uzbekistan was led by paediatric haematologist Dr Sapura Ibragimova, and included policy-makers, paediatric oncologists (cancer specialists), haematologists (blood specialists), evidence-based medicine professionals and representatives from patient groups. Despite the added challenges of the COVID-19 pandemic, this multidisciplinary team attended the training and worked together to produce an evidence-informed report and action plan for the prevention and control of childhood cancer. Notably, Dr Elmira Basitkhanova, Deputy Minister of Health, attended the opening webinar, demonstrating high-level support for evidence-informed policy-making.

The training had a good combination of theory and practice and was really well organized. I hope that it will continue in other areas.

**Nigora Muratova, Evidence-based Medicine Centre,
Tashkent Institute of Postgraduate Medical Education**

The team appreciated the realistic and pragmatic approach to policy-making: the training helped them not only to harness research evidence but also to understand how to engage and influence policy-makers and to navigate the policy-making system.



Box 2. How WHO supports evidence-informed policy-making

Developing and implementing evidence-informed policies — especially if this is to be done in a sustainable way — requires knowledge, skills and supportive leadership at a local level.

EVIPNet Europe supports Member States in the WHO European Region to build capacity and strengthen leadership for evidence-informed policy-making. This promotes a long-term vision of countries independently developing and implementing evidence-informed policies to strengthen their universal health coverage and improve health outcomes for all citizens.

The project in Uzbekistan was supported by EVIPNet Europe, the WHO Regional Office for Europe cancer control team, and the WHO Country Office in Uzbekistan along with a team of experienced facilitators. It was funded by the United States Agency for International Development as part of a broader effort to strengthen the health information system in Uzbekistan and by a grant of St Jude children's research hospital to WHO.



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Working together and exceeding expectations

Participants initially had mixed expectations about the value of the training but quickly began to see the potential benefits as they worked together to develop the report.

The clinicians participating in the training were driven by a fierce determination to improve outcomes for their patients, but most of the participants were relatively new to evidence-informed policy-making. Initially, some members of the Working Group did not understand why they should participate in the webinars. Many had the impression that policy-making is an activity exclusively reserved for ministers and civil servants and, therefore, considered that they would not be able to make a meaningful contribution to policy development.

Experts in the working group started to voice *their* problems and came forward with shortcomings that need to be improved. Once people acknowledge there is a problem, and voice it, then we can look for ways to solve it.

**Munira Khodjakhanova, Director,
Public Foundation Ezgu Amal**

However, based on the training, the team quickly understood how they could put the theory of evidence-informed policy-making into practice to help them to solve the problems that they faced in their various clinical and professional practices. Working together, they identified problems affecting childhood cancer care in Uzbekistan and looked for promising policy solutions. The Working Group identified issues by looking at existing research evidence, but also by drawing on their own experiences as clinical and policy specialists in Uzbekistan. Open discussion about childhood cancer care in Uzbekistan enabled the team to reach agreement about the nature of the problem and its causes, and to start formulating solutions.

Drawing on the knowledge and skills acquired in the webinars, and using EVIPNet tools and resources, the Working Group developed a policy-focused evidence-informed report.

I think we changed the mentality of the *professionals* in the working group. Now they believe they can develop policy and participate fully in the policy-making process.

**Nazokat Kasymova, National Professional Officer,
WHO Country Office in Uzbekistan**

The evidence-informed report

The report sets out the situation in relation to childhood cancer in Uzbekistan, suggests a series of concrete, evidence-informed policy solutions and identifies barriers to their implementation.

The report identified that inadequate governance, financing and delivery arrangements contributed to poor childhood cancer health outcomes. It also noted that Uzbekistan lacked a functioning cancer registry or patient database, which limited the amount and quality of local data available to inform cancer policy and care. Moreover, before the start of the project in 2020, paediatric haematology and oncology remained two separate specialties in Uzbekistan, with limited coordination between them. In most high- and middle-income countries in the WHO European Region, the two are combined as a paediatric haematology–oncology specialism, which focuses on blood disorders and cancers in children.

In Uzbekistan, insufficient financing for medicines, inpatient and outpatient treatment, chemotherapy, diagnostic tools and palliative care still limits the quality of paediatric haematological and oncological services that can be provided. Screening programmes are limited, particularly in remote areas, resulting in delayed prevention and late diagnosis. Moreover, there are no national-level professional standards or clinical guidelines and protocols in line with international standards for paediatric oncology. Low salaries, poor working conditions and high patient numbers per doctor and nurse make clinical work in this field unattractive.

The report contains specific policy suggestions, based on international research into best practice in childhood cancer care.

Box 3. Policy suggestions in the evidence-informed report

- Introduce a national registry for children with cancer.
- Create a new, joint specialism in haematology–oncology.
- Design and launch an integrated paediatric haematology–oncology course.
- Develop professional standards for clinical specialists in paediatric haematology and oncology.
- Plan centralized government procurement of the medications and reagents needed for modern diagnosis and treatment of childhood cancer.

The report also details barriers to implementing evidence-informed policies in the current social and political context in Uzbekistan. These included patients' fears that they will be unable to pay for expensive treatment out of pocket; lack of professional expertise and motivation linked to inadequate incentives for clinical oncologists and haematologists; and low commitment and accountability at both institutional and health system levels to improve the provision of cancer care for children.

Putting evidence-informed policies into practice

Several options identified in the report have already been put into action.

Thanks to efforts by the working group, we have achieved results. The President was bold enough to admit the problems facing childhood cancer care and called upon everyone to change the situation. Thanks to his political will *and* action there are very serious changes in this area, including increased financing.

Eldor Iskhakov, Head of Department of Hematology and Blood Transfusion,
Center for the Professional Education of Medical Workers under the Ministry of Health

As a result of this work, childhood cancer has received increasing attention from the highest level of Government. In May 2021, the President of the Republic of Uzbekistan, Mr Shavkat Mirziyoyev, signed a resolution committing to improving haematological and oncological services in Uzbekistan and announced his support for a new joint centre for paediatric oncology and haematology. He committed significant financial resources from the State budget to cancer care across 2021–2024, including for childhood oncology and haematology services. The First Lady of Uzbekistan has also announced her support for initiatives to improve childhood cancer care. Professionals in the national Working Group were inspired to see increased commitment and institutional support for childhood cancer care.

The problem of poor and avoidable childhood cancer outcomes is now seen as a priority in Uzbekistan. Deputy Minister Dr Elmira Basitkhanova used the evidence-informed report to advocate with the Government and to explain the importance of the issue to other ministers. Poor outcomes in Uzbekistan mean that childhood cancer is seen as a death sentence, and the report has raised awareness that better treatment and outcomes are achievable. Therefore, the Ministry of Health now views the Working Group as capable of contributing to policy and strategy and includes them in other activities and meetings.

We did our best before, but our successes were rather *modest*, and we didn't see much change. We always had hope, but with this project we are seeing some real change.

Indira Erimbetova,
Paediatric Haematologist

In addition to this high-profile support, actions have already been taken in line with the policy suggestions in the evidence-informed report. Changes have been made to the postgraduate medical curriculum, including the creation of a new paediatric haematology–oncology specialism and the development and authorization of an integrated paediatric haematology–oncology course. Work has started on new training curriculums for early diagnosis of childhood cancer and for childhood cancer nursing. These are important steps towards bringing cancer care in Uzbekistan in line with international standards and practice.

Capacity–building and collaborative working

As well as tangible policy outcomes, the project produced benefits that will contribute to future evidence-informed policy-making in this area and more widely in Uzbekistan.

It is best to help professionals – they are in the mid stage of their career, and some of them will sooner or later become ministers or heads of centres. By training them and involving them in the process, they will remember the importance of evidence-informed policy-making.

**Vitaly Smelov, Medical Officer,
WHO Regional Office for Europe**

As well as saving the lives of children with cancer, the evidence-informed, cross-sectoral approach helps to strengthen the whole system. Increased support for evidence-informed policy in ministries of health and governments has the potential to spread to other areas of practice and to help many more people.

One of the main aims of EVIPNet is to advocate and build capacity for evidence-informed policy-making at all levels of government and professional practice. In Uzbekistan, there is now a group of professionals who have the skills and knowledge to develop evidence-informed policies and navigate policy-making processes. WHO will continue to work with them as focal points, alongside the Ministry of Health, to further develop the childhood cancer programmes.

We worked together as a team, and the team building and collaboration between all participants continued after the training.

**Sapura Ibragimova,
Paediatric Haematologist**

The project required close collaboration and team work between professionals from a variety of institutions and with differing expertise who would not normally work together. Consequently, participants in this multidisciplinary group needed to explore and express their different perspectives and to collectively agree on the best way forward. Alignment of stakeholders on key issues provided a strong basis for advocating for evidence-informed policies and will enable the Working Group to build on their successes.

We had an excellent team and we did a great job together. We know that you have to set your objectives properly, plan your work, and be persistent in pursuing your goals.

**Indira Erimbetova,
Paediatric Haematologist**

The basis for this collaborative work was thorough and realistic planning, objective setting and clear formulation and appraisal of ideas; this was emphasized in the training. The evidence-informed approach generated a well-defined, shared starting point for these dialogues. This helped participants to concentrate on specific areas together and to maintain a focus on the ultimate goals of the work. Many participants expressed their admiration for the way their colleagues worked together as a team, and for the enthusiasm and commitment shown by all participants.



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Overcoming challenges and learning lessons

Despite the successes of the project, the team had to overcome challenges in order to achieve results. There remain barriers to evidence-informed policy-making in Uzbekistan.

The Working Group established a culture of open and honest communication among the members and was able to reach alignment in characterizing the problem and identifying solutions. However, members also encountered resistance to their ideas from some clinical colleagues and policy-makers. By using research evidence to frame and outline the problem and to identify solutions, the Working Group was able to start dialogue with these dissenting individuals and to convince them of the benefit of the proposed policies. Securing high-level support from the President and Deputy Minister also helped to overcome resistance at the managerial level.

Much of the research about new medical technologies and gold standard clinical practice is published in English yet many clinicians in Uzbekistan cannot speak or read English to a professional level and are limited to Russian-language publications. This means that they have limited access to international research and are largely unable to publish their own work in international journals. Several members of the team involved in this childhood cancer project are now learning English to strengthen their future contributions to evidence-informed practice and policy-making. However, in general, this remains a significant barrier to evidence-informed policy-making in Uzbekistan, which must be addressed with targeted training of clinicians, researchers and policy-makers.

A major ongoing challenge faced by professionals and policy-makers in Uzbekistan is the limited capacity for data collection and analysis in the country. The evidence-informed approach and constructive, non-judgemental ethos adopted by the Working Group has contributed to shifting this in relation to childhood cancer policy, but there is more work to be done. Health-care services are not transparent about their own internal processes and outcomes and are reluctant to cooperate or share data. Moreover, sharing even anonymized personal data is prohibited by law in Uzbekistan unless written consent is provided. There are ongoing health information strengthening and e-health projects in Uzbekistan, but it is likely that regulatory change is needed to establish a functioning, representative childhood cancer registry.

There is work to be done, but the success of this childhood cancer project shows that policy-making to improve health outcomes is achievable in Uzbekistan.

Next steps

The Working Group and WHO are enthusiastic to build on these achievements.

Members of the Working Group are using the skills they have learned through the training to contribute to a national cancer control plan: a five-year comprehensive action plan for cancer care led by the Ministry of Health, which will cover not just childhood cancer but all cancer specialities. This will help to secure the political, institutional and financial support necessary to create sustained improvements in the treatment and diagnosis of childhood cancer, and particularly in the provision of adequate palliative care.

WHO will continue to support policy development and strengthened health-care provision for improved childhood cancer diagnosis, treatment and outcomes via technical advice and methodological guidance. The cancer control team in the WHO Regional Office for Europe and the WHO Country Office in Uzbekistan are planning an in-depth study on barriers to the diagnosis of cancer in Uzbekistan and will provide recommendations to the Ministry of Health on how the system can be strengthened.

Clinicians and researchers in Uzbekistan are especially keen to develop new treatment guidelines and clinical standards for childhood cancer care that are in line with international standards. Among other benefits, this work will raise the profile of cancer nursing and help to change perceptions of palliative care and survivorship – two crucial areas of cancer care which are currently overlooked in Uzbekistan.

Now that the benefits of evidence-informed policies in this area are better understood, the WHO Regional Office for Europe cancer control team has confidence that the support from the President of the Republic of Uzbekistan, the Ministry of Health and the First Lady of Uzbekistan will translate into longer-term support for childhood cancer. Groups representing patients and nongovernmental organizations will play an important role holding policy-makers to account and keeping up momentum.

We are planning to have quarterly briefings with specialists and policy-makers. We will ask for reports and feedback from Government about the implementation of decrees and policies, and the challenges and problems that specialists are facing. If there are problems, we must identify them and make them known so we can look for solutions.

**Munira Khodjakhanova,
Director of Public Foundation Ezgu Amal**

The success of this work and the promise of continued progress show the potential for the country to help and support other countries and to become a regional player in the area of evidence-informed childhood cancer care.

Ongoing work

The WHO Regional Office for Europe continues to support evidence-informed policy-making across Europe by training professionals, assisting in the development of evidence briefs for policy and advising on policy dialogues and policy implementation.

Country-level teams in the WHO European Region are currently working with EVIPNet to develop evidence briefs for policy on topics such as tackling antimicrobial resistance, improving long-term care, preventing noncommunicable diseases and reducing salt consumption. They are building on EVIPNet training, tools and expertise to build capacity across the system and garner support for evidence-informed policy solutions at the highest level.



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WHO/EURO:2022-5884-45649-65537

World Health Organization Regional Office for Europe

UN City, Marmorvej 51
DK-2100 Copenhagen Ø
Denmark

Tel.: +45 45 33 70 00

Fax: +45 45 33 70 01

Email: eurocontact@who.int

Website: www.who.int/europe