


BRIEF REPORT

A teratology information system in vernacular: Closing an information gap

Erika Patskun^{1,2} | Lyubov Yevtushok^{1,3} | Nataliia Zymak-Zakutnia^{1,4} |
Serhiy Lapchenko^{1,5} | Diana Akhmedzhanova^{1,4} | Wladimir Wertelecki¹ 

¹OMNI-Net Ukraine Birth Defects Program, Rivne, Ukraine

²Uzhhorod National University, Uzhhorod, Ukraine

³Rivne Regional Medical Diagnostic Center, Rivne, Ukraine

⁴Khmelnysky City Children's Hospital, Khmelnytsky, Ukraine

⁵Volyn Regional Territorial Medical Mother and Child Health Care Center, Lutsk, Ukraine

Correspondence

Wladimir Wertelecki, 36, 16 Lypnia St, Rivne 33028, Ukraine.

Email: werteleckiomni@gmail.com

Abstract

Background: Leading Teratology Information Systems (TIS) arose in major industrial nations and are mostly in English. The prevalence of anglophone speakers in Ukraine is among the lowest in Europe. A TIS in Ukrainian (UTIS) seeks to diminish an information gap concerning teratogens. The process and results related to UTIS are applicable to formulations of other TIS in vernacular languages.

Methods: Implementation of a free-access UTIS and analysis of utilization patterns. UTIS provides access to articles in Ukrainian (AU) which are summaries extracted from leading international TIS and other sources. AU are revised at least tri-annually.

Results: UTIS provides access to over 1,100 AU accrued since 2016 to the present. The number AU views increased from nearly 30,000 (2016) to over 80,000 (2020); the number of visitors increased from 3,500 to 58,000 during the same periods. The highest percent of users per urban population (2.09, 1.77, and 1.72) was in Ternopil, Ivano-Frankivsk, and Kyiv (capital), respectively; the lowest was in Odesa (0.17).

Conclusions: UTIS reduced an information gap in Ukraine concerning teratogenic risk factors. The process can be implemented elsewhere relying on generally available local resources.

KEYWORDS

birth defect, information, malformation, teratogen, vernacular

1 | INTRODUCTION

Teratology Information System (TIS) fulfill a major societal and health care role. TIS information provides guidance for optimal modes of early recognition, health care, and prevention of developmental anomalies. Concurrently, such information reduces needless fears that may lead to unnecessary medical procedures, including terminations of pregnancies. TIS arose in advanced industrial societies. Their contents are mostly in English, followed by other languages, including

French, German, Spanish, and a few others. In Ukraine, the prevalence of English speakers is the lowest in Europe. Also, Ukrainians are, arguably, rather unusually aware of teratogenic risks as a consequence of the Chernobyl disaster. These, among other circumstances, motivated the creation of a TIS in Ukrainian (UTIS; Ceulemans, Fortuin, Van Calsteren, Allegaert, & Foulon, 2020; Chambers, 2011; ENTIS, 2021; Hancock, Koren, Einarson, & Ungar, 2007; MotherToBaby, 2021; Reprotox, 2021; Schaefer, 2011; Wertelecki, 2010; Wertelecki et al., 2014; Wikipedia, 2021).

UTIS was developed by members of OMNI-Net in Ukraine, an international non-for-profit organization registered in Kyiv and dedicated to the early recognition, care, and prevention of developmental disorders (Wertelecki et al., 2018). A free access UTIS website is operational since 2016 (<http://utis.in.ua/>).

2 | METHODS

The core component of UTIS are articles in Ukrainian (AU) concerning particular teratogens. The contents are extracts and adaptations from leading information sources including various TIS (Briggs, Freeman, Towers, & Forinash, 2017; Drugs and Lactation Database, 2021; E-lactancia, 2021; MotherToBaby, 2021; Reprotox, 2021; Schaefer, Peters, & Miller, 2015). The most numerous AU are concerned with pharmacologic agents sold in Ukraine and include, whenever possible sections concerned with: therapeutic category; market names; active compounds; brief pregnancy and breastfeeding recommendations; experimental animal studies; human pregnancy, fetal risk and breastfeeding summaries; general reproductive risks; references; and date. UTIS also includes AU regarding other salient teratogenic risk factors, mostly of environmental nature. The accrual of AU was gradual and continues. The Editor and Associate Editor select the themes and review the contents. In addition, the contents are also reviewed, according to the themes, by a member of OMNI-Net or an external expert. AU are updated at least tri-annually. Each AU also includes a satisfaction questionnaire for users to evaluate the contents. User's evaluations are voluntary and anonymous. Analyses of patterns of use are mostly based on Google Analytics data of the UTIS

website (Semrush Blog, 2021). The cited demographic data were obtained from Wikipedia (Wikipedia, 2021).

In Figure 1 are shown the yearly number of UTIS users and number of pages opened. In Table 1 are shown 13 of the most populous cities in Ukraine and the percent of UTIS users residing in them.

3 | RESULTS

The number of AU exceeds 1,100 and the themes primarily concern drugs and prevalent environmental teratogens in Ukraine, such as alcohol and Chernobyl ionizing radiation. The themes of the 5% most viewed AU concern critical fetal development periods, infectious diseases, drugs in pregnancy, "aspirin," and ionizing radiation. Analysis of 2,200 user's evaluations indicated that 19% were pregnant women; 32% were "students"; 25% were physicians; and 24% were nurses, relatives of pregnant women, or "others." Regarding AU information, 30% of 1,100 respondents ranked the contents as "fine," 51% as "very good"; 15% as "satisfactory," and 4% as "bad." As of December 31, 2020, UTIS was accessed 290,887 times. Since 2016, the yearly number of users has grown yearly (Figure 1). Over 50% of contacts are from "mobile devices."

In Table 1 are shown the relative frequency of UTIS users residing in 13 of the most populous cities in Ukraine. The highest relative frequency of TIS users reside in the areas of Ternopil, Ivano-Frankivsk, and the capital Kyiv. The lowest relative frequency of TIS users is the populous city of Odesa. Nearly 36% of users reside in relatively smaller population sites.

The majority of UTIS users reside in Ukraine (94%), and others reside in Poland, United States, Germany, and Russia, in that order. The male-female sex proportions

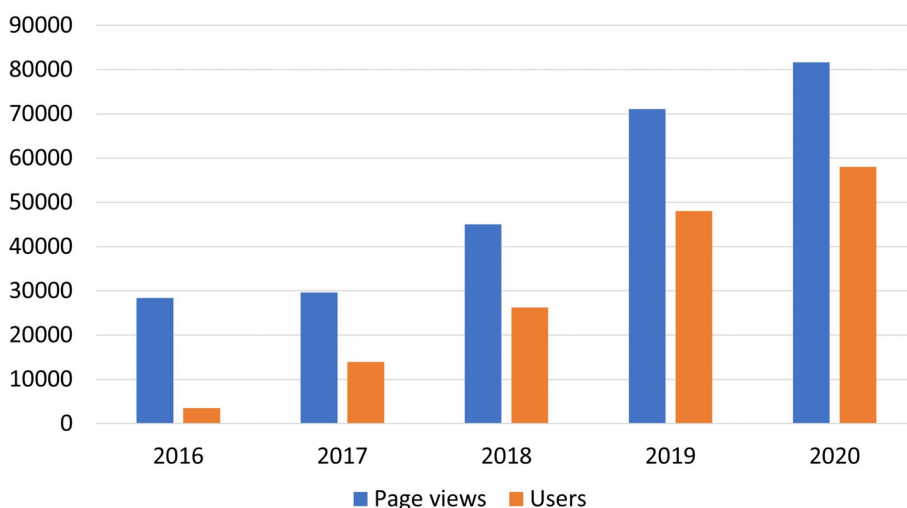


FIGURE 1 Temporal trend of users and page views of UTIS

TABLE 1 UTIS users residing in major urban centers in Ukraine (2016–2020)

| City | Users | % Users | Site population | % of Users per population |
|-----------------|--------|---------|-----------------|---------------------------|
| Kyiv | 49,504 | 33.40% | 2,884,000 | 1,72 |
| Lviv | 11,864 | 8.00% | 721,301 | 1,64 |
| Dnipro | 5,458 | 3.68% | 966,400 | 0,56 |
| Ternopil | 4,521 | 3.05% | 216,384 | 2,09 |
| Ivano-Frankivsk | 4,086 | 2.76% | 230,507 | 1,77 |
| Vinnitsia | 3,571 | 2.41% | 370,834 | 0,96 |
| Kharkiv | 3,155 | 2.13% | 1,419,000 | 0,22 |
| Chernivtsi | 2,706 | 1.83% | 262,276 | 1,03 |
| Rivne | 2,571 | 1.73% | 243,934 | 1,05 |
| Lutsk | 2,353 | 1.59% | 213,950 | 1,10 |
| Khmelnyskyi | 2027 | 1.37% | 265,693 | 0,76 |
| Odesa | 1,658 | 1.12% | 993,120 | 0,17 |
| Uzhhorod | 1,485 | 1.00% | 112,447 | 1,32 |
| Other sites | 53,267 | 35.94% | – | – |

are nearly equal (54% males). The ages of users in the range of 18–24, 25–34, and 35 years of age or greater were 28, 35, and 37%, respectively.

4 | DISCUSSION

The initial and most labor-intensive ongoing central goal of UTIS is the development and dissemination of AU. Like other TIS, most UTIS AU are concerned with pharmaceuticals. However, UTIS also includes AU concerned with prevalent teratogens such as alcohol, ionizing radiation, and treatment of maternal disorders potentially teratogenic, among others. The accrual of AU continues and we estimate that an additional 15–20% is desirable. The dissemination of the contents of UTIS is solely through a dedicated website (<http://utis.in.ua/>). Consultations via e-mail are available but generally few. Nearly 36% of users resided in relatively small population sites, while the rest resided in major urban areas. As shown in Table 1, the largest number of users resided in the capital Kyiv (33%). In terms of the proportion of users per the urban population, Kyiv is the third largest (1.72%) while in Ternopil and Ivano-Frankivsk urban areas the frequency of users is greater, 2.09 and 1.77%, respectively. The lowest frequency of users in an urban area is in Odesa (0.17%). Such contrasts are clues to guide efforts to promote UTIS more effectively.

An ideal of most TIS is expressed by the adage *Every Woman—Every Time*, alluding to the aim of providing women of reproductive age, whenever they receive medical services, with information regarding teratogenic risks they may confront. In practice, OMNI-Net seeks for UTIS

to be attuned to the needs of Family/Patient Organizations (FPO) as well as specialized health care providers (SCP). In contrast to FPO main focus on particular developmental anomalies, OMNI-Net and UTIS address the early recognition, treatment, and prevention of prevalent developmental anomalies. The creation of tri-partite partnerships (TPP) linking FPO and SCP with OMNI-Net and UTIS seek to promote both goals. To test the TPP strategy, a “Spina Bifida TPP” was established to increase and strengthen FPO and SCP as well as to advocate the prevention of spina bifida and related anomalies. In fact, the prevalence and mortality associated with spina bifida in Ukraine is the highest in Europe (Wertelecki et al., 2017). The “Spina Bifida TPP” calls for Ukraine to legislate and implement folic acid flour fortification programs to reduce the frequency of spina bifida and related disorders, as observe in other nations where such was implemented, by at least 50%. A proposal for legislation mandating folic acid fortification in Ukraine is currently re-submitted to the Parliament by several sponsors including OMNI-Net and a Spina Bifida FPO. The experience from the “Spina Bifida TPP” is expected to facilitate the creation of other TPPs, such as an “Alcohol TPP.”

5 | CONCLUSIONS

The pattern of utilization of UTIS indicates that it reduces the information gap in Ukraine concerning teratogenic risks. Furthermore, the experience of creating UTIS also indicates that other TIS in vernacular languages can arise elsewhere with relative ease and relying on generally available local resources. UTIS can also

serve as a catalyst stimulating the formation of TPPs to synergistically promote the strengthening of FPO, SCP, and concurrently to call for prevention programs of a variety of developmental anomalies.

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CONFLICTS OF INTEREST

None.

AUTHOR CONTRIBUTIONS

All authors have read and agreed to the contents of this manuscript; the conceptualization of the report was contributed by Erika Patskun, Lyubov Yevtushok, and Wladimir Wertelecki; the methodology was defined by Erika Patskun, Lyubov Yevtushok, Serhiy Lapchenko, Diana Akhmedzhanova, and Wladimir Wertelecki; the software was developed by Serhiy Lapchenko; the analysis was performed by Serhiy Lapchenko, Diana Akhmedzhanova, and Wladimir Wertelecki; the writing was led by Erika Patskun, Lyubov Yevtushok, and Nataliia Zymak-Zakutnia; and review and editing was by Erika Patskun and Wladimir Wertelecki.

DATA AVAILABILITY STATEMENT

By reasonable written requests.

ORCID

Wladimir Wertelecki  <https://orcid.org/0000-0001-5864-5985>

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