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## **Evaluation of Knowledge, Attitudes, and Practices towards Vaccination among Patients with Spina Bifida in Ukraine**

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Patients with spina bifida (SB) face an increased risk of infection due to frequent exposure to medical procedures and visits to healthcare centers, including rehabilitation centers. Infection can lead to complications in kidneys and urinary bladder, disrupt rehabilitation efforts, and reduce the quality of life.

**Purpose** — to assess the knowledge, attitudes, and practices related to vaccination among patients with SB and identify the reasons for the low vaccination rates in this group of children.

**Materials and methods.** An anonymous online survey was conducted among 56 parents of patients with SB. The questionnaire evaluates the knowledge (10 questions), attitudes and practices (4 questions) towards vaccination among parents of patients with SB in Ukraine. The results were analyzed using standard procedures with Statistica StatSoft 6.0 software package. Continuous variables were expressed as a mean and standard deviation (SD). The comparison of frequency parameters was performed using the Chi-square test. The differences between the parameters were statistically significant at  $p < 0.05$ .

**Results.** Overall, parents demonstrated good knowledge about the role of vaccines in preventing serious diseases (61.7% gave correct answers), and the percentage of correct answers did not significantly differ between vaccinated, partially vaccinated, or unvaccinated groups of children. However, only 12.5% of SB patients were fully vaccinated and 51.8% were completely unvaccinated. Among the unvaccinated, the majority (55.2%) indicated non-recommendation by specialist doctors (neurosurgeon, neurologist, etc.) as the main reason. Primary care physicians were less likely to not recommend vaccination. Delayed vaccination was primarily due to fear of adverse reactions (40%). Despite low vaccination rates, parents generally had a positive attitude towards vaccination (only 5.4% against). Doctors remained the most influential source of information (63.4%).

**Conclusions.** A study suggests a need to enhance knowledge among healthcare professionals, increase public awareness, and provide education within patient groups to improve immunization coverage and protect SB children from preventable infectious diseases.

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**Keywords:** spina bifida, vaccination, disability, knowledge, attitudes, and practices

### **Оцінка знань, ставлення та практик щодо вакцинації пацієнтів зі spina bifida в Україні**

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Пацієнти зі spina bifida (SB) мають підвищений ризик інфікування через часті медичні процедури та відвідування медичних центрів, зокрема реабілітаційних центрів. Інфекція може призводити до ускладнень із боку нирок і сечового міхура, порушувати процес реабілітації та знижувати якість життя.

**Мета** — оцінити знання, ставлення та практики, пов'язані з вакцинацією серед пацієнтів зі SB; виявити причини низького рівня вакцинації в цій групі дітей.

**Матеріали та методи.** Проведено анонімне онлайн-опитування 56 батьків дітей, хворих на SB. Анкета оцінювала знання (10 запитань), ставлення та практику (4 запитання) щодо вакцинації дітей, хворих на SB. Результати проаналізовано за допомогою програмного пакету «Statistica StatSoft 6.0». Безперервні змінні виражено як середнє значення та стандартне відхилення (SD). Порівняння частотних параметрів проведено за допомогою критерію  $\chi^2$ -квадрат. Відмінності між параметрами були статистично достовірними за  $p < 0,05$ .

**Результати.** Загалом батьки показали хороші знання про роль вакцин у профілактиці серйозних захворювань (61,7% дали правильні відповіді), причому відсоток правильних відповідей суттєво не відрізнявся між щепленими, частково щепленими та невакцинованими групами дітей. Проте лише 12,5% хворих на SB були повністю вакцинованими, а 51,8% — повністю невакцинованими. Серед невакцинованих більшість (55,2%) вказали на рекомендацію лікарів-спеціалістів (нейрохірурга, невролога тощо) як основну причину. Лікарі первинної ланки рідше не рекомендували щеплення. Затримка вакцинації була насамперед пов'язана зі страхом побічних реакцій (40,0%). Незважаючи на низький рівень вакцинації, загалом батьки позитивно ставилися до вакцинації (проти лише 5,4%). Найповнішим джерелом інформації для батьків були лікарі (63,4%).

**Висновки.** Дослідження свідчить про необхідність поліпшення знань серед медичних працівників, підвищення обізнаності громадськості та забезпечення навчання в групах пацієнтів для збільшення охоплення імунізацією та захисту дітей зі SB від інфекційних захворювань, яким можна запобігти.

Автори заявляють про відсутність конфлікту інтересів.

**Ключові слова:** spina bifida, вакцинація, інвалідність, знання, ставлення, практика.

## Introduction

**S**pina bifida (SB) is one of the most common neural tube defects (NTDs) [5]. SB develops as a result of incomplete closure of the neural tube during the first month of gestation and can occur anywhere along the spine [4]. Eliminating the defect at an early age improves the prognosis of children, but does not lead to complete recovery. Impairments of the functions of organs and systems develop during the first years of life and lead to disability [5]. The degree of impairments depends on the severity and localization of the defect [4]. Hydrocephalous, tethered cord, Chiari II dysfunction, neurogenic bladder dysfunction, neurogenic bowel dysfunction, spasticity, neuromuscular scoliosis and skeletal deformation, osteoporosis, obesity and overweight, psychological problems, social isolation – this is an incomplete list of problems faced by patients with SB, which requires a multidisciplinary approach and lifelong medical care [8,12].

Children with SB may be involved in many surgical procedures during their life depending on their condition and have been followed up by different specialists, including neurosurgeon, neurologist, pediatrician, urologists, physical therapist, etc.

Neurological disorders dominate in patients with SB and cause impairments in other organs and systems. The possibility of vaccination side effects in patients with neurological manifestations has been discussed for several decades [9,15]. Previous concerns mainly focused on vaccines containing pertussis components. However, research shows the safety of vaccines with acellular pertussis components in children with neurological pathology [17]. Moreover, patients with SB are at an increased risk of infection due to frequent exposure to medical procedures and visits to healthcare centers, including rehabilitation centers. Each infection can lead to complications in the kidneys and urinary bladder, disrupt rehabilitation efforts, and reduce the quality of life. Therefore, vaccination is an important preventive measure for children with SB to protect against infectious diseases. The Centers for Disease Control and Prevention (CDC) recommend that patients with SB should receive all routine childhood vaccinations, including live vaccines. In addition, the CDC recommends some additional vaccines for these individuals, such as pneumococcal, influenza, and meningococcal vaccines. Despite

dispelling most myths regarding the adverse effects of vaccines on neurodevelopment in children, and the development of complications in patients with neurological manifestations, there is significant hesitancy among patients and physicians. Following patients with SB, we have observed a low level of vaccination coverage among them [1].

The **purpose** of the study was to assess the knowledge, attitudes, and practices related to vaccination among patients with SB and identify the reasons for the low vaccination rates in this group of children.

## Materials and methods of the study

We conducted an anonymous online survey among parents of patients with SB. The online survey was done in the period February–March 2023 among respondents that were registered in Ukrainian patient's Viber group of the Association of parents of children with SB and hydrocephalus «Lights of Spirit». Out of 149 participants of Viber group 56 respondents (parents of children with SB) from all regions of Ukraine answered the questionnaire.

The questionnaire was developed by doctors and tested by parents of patients with SB. Some questions about attitudes were adapted from the survey about seasonal influenza vaccine [10]. There were 18 questions in the survey, 2 of them with more than one possible answer. All questions could be divided into three sections: demographic data – 4 questions; assessment of the knowledge about vaccine-preventable infections – 10 questions; attitudes and practices for vaccination – 4 questions. Respondents filled out the survey through the Google Forms. The participants were informed about the purpose of collecting the information and how it would be used.

The results were analyzed using standard procedures with Statistica StatSoft 6.0 Software package. Continuous variables were expressed as a mean and standard deviation (SD). The comparison of frequency parameters was performed using the Chi-square test. The differences between the parameters were statistically significant at  $p < 0.05$ .

## Results of the study

A total of 56 respondents answered questions about vaccination. Demographic characteristics of the patients and respondents as well as answers to the questions of the survey of all respondents are shown in table 1. The average age of the patients was  $8.0 \pm 4.9$  years, and ranged from 8 months

Table 1

**Sociodemographic characteristics of all respondents and the age of patients with SB**

Characteristics	n	%
Age of the patients, years, range	8.0±4.9 8 months – 18 years	
Age of the respondents, years, range	35.7±6.7 21–50	
Education level:		
high school	33	58.9
secondary education	22	39.3
incomplete secondary education	1	1.8
Financial situation:		
difficult	13	23.2
manageable	37	66.1
comfortable	4	7.1
no answer	3	5.4

to 18 years. The average age of the parents who answered the questionnaire was 35.7±6.7 years and ranged from 21 to 50 years. Individuals with high school educational level prevailed among the respondents (58.9%). In most patients, the financial situation was manageable (66.1%), however, 23.2% of respondents indicated a difficult financial situation.

Knowledge, attitudes, and practices towards vaccination among the respondents are presented in Table 2. The overall percentage of correct answers for the knowledge assessment ranged from 21.4% to 91.1%. In most cases, respondents provided correct answers and demonstrated good knowledge about the dangers of diphtheria, tetanus, pertussis, and rubella. Some respondents faced difficulties when answering questions about the severity of measles depending on age, the role

of the hepatitis B vaccine in preventing liver cancer, and the necessity of additional vaccinations for chronic diseases, where the percentage of correct answers was less than half.

Among the reason why a child is not vaccinated, «not recommended by a specialist doctor» was noted most frequently (41.1%), followed by «fear of adverse reactions» (25%), and other reasons (32.1%). Only 3 (5.4%) respondents were against vaccination in general, although only one of them believed that nothing can change in the future. Overall, only 4 (7.1%) reported that nothing can change in the future, the rest suggested that they could change their opinion. Additional information from doctors can influence a change in respondents' opinions in the majority of cases (64.3%). Other parents whose children have similar health problems (32.1%) also play a sig-

Table 2

**Knowledge, attitudes and practices towards vaccination among the respondents (n=56)**

Question	n	%
The diphtheria is a contagious disease		
true	50	89.3
false	–	–
do not know	6	10.7
The diphtheria is a life-threatening disease		
true	51	91.1
false	1	1.8
do not know	4	7.1
Tetanus can be infected due to injury		
true	43	76.8
false	6	10.7
do not know	7	12.5
Tetanus can lead to the death of a child		
true	46	82.1
false	4	7.1
do not know	6	10.7
You can get pertussis at any age		
true	39	69.6
false	7	12.5
do not know	10	17.9
Measles is more severe in preschool children than in teenagers		
true	12	21.4
false	27	48.2
do not know	17	30.4

Continuation of the Table 2

Question	n	%
Vaccination against hepatitis B can help to prevent the development of liver cancer		
true	15	26.8
false	15	26.8
do not know	26	46.4
Surgical interventions can increase the risk of hepatitis B infection		
true	31	55.4
false	9	16.1
do not know	16	28.6
Rubella during pregnancy can lead to the development of severe birth defects		
true	43	76.8
false	2	3.6
do not know	11	19.6
Additional vaccines are recommended for children and adults with chronic diseases		
true	16	28.6
false	19	33.9
do not know	21	37.5
Is your child vaccinated?		
yes, completely according to the scheduler	7	12.5
yes, with a violation in the scheduler	10	17.9
partly, with a violation in the scheduler	10	17.9
no	29	51.8
Please indicate the reason your child did not receive vaccination		
not recommended by a specialist doctor	23	41.1
not recommended by primary care physician	4	7.1
lack of information	4	7.1
fear of adverse reactions	14	25
against vaccination in general	3	5.4
vaccines are not effective	0	0
other	18	32.1
Do you think that something can change your mind in the future?		
yes	25	44.6
no	4	7.1
maybe	27	48.2
What can help to change your mind regarding the vaccination?		
additional information from doctors	36	64.3
information from other sources — television, the Internet, newspapers	2	3.6
information from other parents whose children have the same health problems	18	32.1
recommendations from friends or parents	1	1.8
other reasons	14	25

Table 3

Socio-demographic characteristics of all respondents and age of patients with SB based on the vaccination status

Question	Vaccinated completely (n=7)	Vaccinated with delay (n=10)	Partly vaccinated (n=10)	Unvaccinated (n=29)
	n (%)	n (%)	n (%)	n (%)
Age of the patients, M±SD; range, years	7.9±4.4; 2.5–15	9.2±3.7; 2–14	6.7±4.1; 1.5–13	8.1±5.6; 0.4–18
Age of the respondents, M±SD; range, years	38.9±6.8; 30–50	34.2±5.2; 24–45	35.7±6.1; 26–48	35.4±7.1; 21–49
Education level				
high school	5 (71.4)	4 (40)	7 (70)	17 (58.6)
secondary education	2 (28.6)	6 (60)	3 (30)	11 (37.9)
incomplete secondary education	–	–	–	1 (3.5)
Financial situation				
difficult	2 (28.6)	3 (30)	2 (20)	6 (20.7)
manageable	3 (42.8)	5 (50)	7 (70)	21 (72.4)
comfortable	–	2 (20)	1 (10)	1 (3.4)
no answer	2 (28.6)	–	–	1 (3.4)

Table 4

**Knowledge about vaccines among the respondents based on the vaccination status**

Question	Vaccinated completely (n=7)	Vaccinated with delay (n=10)	Partly vaccinated (n=10)	Unvaccinated (n=29)
	n (%)	n (%)	n (%)	n (%)
The diphtheria is a contagious disease				
true	6 (85.7)	9 (90)	10 (100)	25 (86.2)
false	—	—	—	—
do not know	1 (14.3)	1 (10)	—	4 (13.8)
The diphtheria is a life-threatening disease				
true	5 (71.4)	9 (90)	10 (100)	27 (93.1)
false	1 (14.3)	—	—	—
do not know	1 (14.3)	1 (10)	—	2 (6.9)
Tetanus can be infected due to injury				
true	5 (71.4)	8 (80)	9 (90)	21 (72.4)
false	1 (14.3)	—	1 (10)	4 (13.8)
do not know	1 (14.3)	2 (20)	—	4 (13.8)
Tetanus can lead to the death of a child				
true	6 (85.7)	9 (90)	9 (90)	22 (75.8)
false	—	—	—	4 (13.8)
do not know	1 (14.3)	1 (10)	1 (10)	3 (10.3)
You can get pertussis at any age				
true	5 (71.4)	6 (60)	8 (80)	20 (69)
false	—	3 (30)	1 (10)	3 (10.3)
do not know	2 (28.6)	1 (10)	1 (10)	6 (20.7)
Measles is more severe in preschool children than in teenagers				
true	1 (14.3)	2 (20)	4 (40)	4 (13.8)
false	2 (28.6)	6 (60)	4 (40)	16 (55.2)
do not know	4 (57.1)	2 (20)	2 (20)	9 (31.0)
Vaccination against hepatitis B can help to prevent the development of liver cancer				
true	3 (42.8)	3 (30)	5 (50)	4 (13.8)*
false	3 (42.8)	—	1 (10)	11 (37.9)
do not know	1 (14.3)	7 (70)	4 (40)	14 (48.3)
Surgical interventions can increase the risk of hepatitis B infection				
true	4 (57.1)	4 (40)	6 (60)	17 (58.6)
false	2 (28.6)	1 (10)	2 (20)	4 (13.8)
do not know	1 (14.3)	5 (55)	2 (20)	8 (27.6)
Rubella during pregnancy can lead to the development of severe birth defects				
true	6 (85.7)	6 (60)	10 (100)	21 (72.4)
false	—	—	—	2 (6.9)
do not know	1 (14.3)	4 (40)	—	6 (20.7)
Additional vaccines are recommended for children and adults with chronic diseases				
true	2 (28.6)	5 (50)	3 (30)	6 (20.7)
false	3 (42.8)	4 (40)	2 (20)	10 (34.5)
do not know	2 (28.6)	1 (10)	5 (50)	13 (44.8)
Total				
Correct answer	44 (62.8)	65 (65)	74 (74)	179 (61.7)
Incorrect answer	11 (15.7)	10 (10)	11 (11)	42 (14.5)
Do not know	15 (21.4)	25 (25)	15 (15)	69 (23.8)

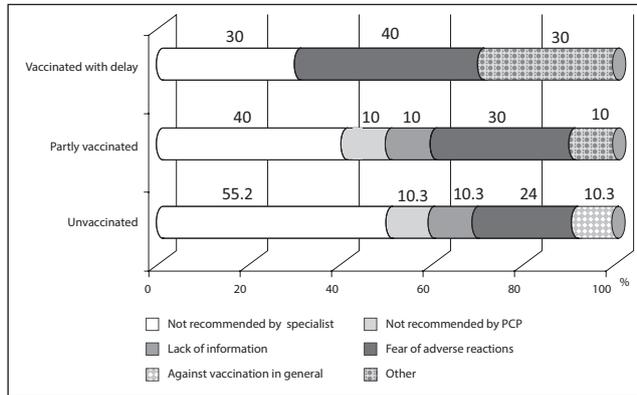
Note: \* — P=0.0191 between partly vaccinated and unvaccinated.

nificant role in changing opinions. According to the survey results, parents have little trust in other sources of information, including the Internet and TV.

To identify factors influencing the vaccination of children with SB, we analyzed the demographic characteristics (Table 3), knowledge (Table 4), and attitudes toward vaccinations based on the vaccination status of the children: completely vaccinated according to the schedule, vaccinated with a violation in the scheduler, partially vaccinated, with a violation in the schedule, not vaccinated. We did not find a significant difference in the age, education, and financial situation of the respon-

dents based on the vaccination status of the children.

In general, knowledge about vaccination showed little variation among respondents in different groups based on vaccination status. Only for the question «Vaccination against hepatitis B can help to prevent the development of liver cancer» the lowest percentage of correct answers was among respondents whose children were unvaccinated, likely being lower than in groups where children were fully or partially vaccinated ( $\chi^2=5.177$ ; P=0.0229). The overall percentage of correct answers also did not differ significantly between groups. Therefore, it was crucial for us



Note: PCP — primary care physicians.

**Fig. 1.** The reasons why the children with SB are unvaccinated

to determine what influenced parents' decision to refuse vaccination. Figure 1 illustrates the factors influencing parents' decisions in each group.

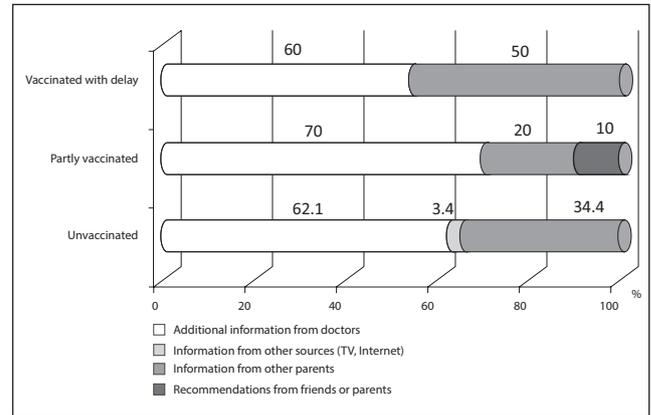
Among the unvaccinated patients, the majority (55.2%) stated that they had not been vaccinated because doctors-specialists (e.g., neurosurgeon, neurologist) did not recommend it. This reason was also indicated in other groups but less frequently. Additionally, parents noted that primary care physicians were much less likely to not recommend vaccination. In the group of patients vaccinated with delay, the main reason was the fear of adverse reactions (40%).

Only three parents, whose children were fully unvaccinated indicated that they would not change their opinion in the future. All remaining parents whose children were unvaccinated or incompletely vaccinated indicated that they could change their minds about vaccination or had already changed. Factors that could change their opinion are illustrated in Figure 2.

Additional information from doctors was most frequently mentioned as a factor that could change parents' opinions in all groups, regardless of vaccination status. For some parents, information from other parents was particularly important, especially in the group of patients who were vaccinated with a delay.

### Discussion

The vaccination of children with neurological diseases has historically been problematic and a matter of debate [9,15,17]. The significant proportion of children with SB who are entirely unvaccinated (51.8%) and the low percentage of those fully vaccinated according to the schedule (12.5%) raise concerns. The vaccination coverage for SB patients in Ukraine is notably lower than that of the general population, as per data from the World



**Fig. 2.** Factors that can change the minds of the parents

Health Organization [16]. Despite a decline in vaccination coverage in 2022 following the Russian invasion in Ukraine, the overall rates range from 62% for hepatitis B vaccination to 73% for the first dose of diphtheria, tetanus, pertussis (DTP) containing vaccine. In 2020, vaccination coverage for all scheduled vaccines was over 80%. In our previous study conducted in 2019 on vaccination coverage of healthy children, only 7.3% of children were completely unvaccinated, significantly lower than the percentage observed in children with SB [3].

The sole study addressing vaccination coverage of children with SB dates back to 1993 and was conducted in the United States (US) [9]. Even at that time, the majority (from 55 to 58%) of children with SB in the US were fully vaccinated according to the recommendation of the American Academy of Pediatrics. However, there were also a high percentage of delays in revaccination for DTP and pertussis immunization, and the vaccination coverage for children with SB was also lower compared to healthy children [9]. The issue of vaccination for children and adults with disabilities, particularly those with neurological pathology, has been raised by other researchers [6] as people with disabilities tend to be under-vaccinated.

Overall, parents demonstrated good knowledge regarding the role of vaccines in preventing serious diseases (61.7% provided correct answers), and the percentage of correct answers did not significantly differ between vaccinated, partially vaccinated, or unvaccinated groups of children. However, on one question regarding the preventable role of hepatitis B vaccination against liver cancer, parents of unvaccinated children provided fewer correct answer (13.8% versus 40.7%,  $p=0.0229$ ).

Our study did not find a significant difference in the vaccination status of children with SB based on the age, education, and financial status of the

respondents. While other studies have indicated the role of parents' education in vaccination adherence; with higher education of parents being both a positive [3,10] and a negative [14] factor in vaccination adherence.

The results of this study differ from others concerning the reasons for vaccine refusal. The most common reason for refusal was that vaccination was not recommended by specialist doctors (41.1%). Among specialist doctors, parents most frequently mentioned neurosurgeons and neurologists. Neurosurgeons, being among the first doctors parents encounter after neonatologists, significantly influence the fate of the child in the first days after birth. Hence, the authority of a neurosurgeon is exceptionally high for parents of children with SB. However, it remains unknown what beliefs or concerns of healthcare professionals led to such recommendations, limiting the current level of understanding of many factors influencing immunization decision-making. This highlights the need to study the issue through surveys among this cohort of doctors and conduct educational initiatives regarding actual contraindications to vaccination.

In contrast, primary care physicians were mentioned much less frequently by parents as those who did not recommend vaccination (overall 7.1%), suggesting that primary care physicians may be better informed about contraindications to vaccination. Primary care physicians play a crucial role in mitigating vaccine hesitancy [7], but this role is particularly vital for the general population. For patients with disabilities, the opinions of specialist doctors they encounter are crucial. In healthy children, according to the results of our previous study, the most common reason for vaccine refusal was fear of side effects (47.5%) [3].

Overall, parents of children with SB generally exhibit a positive attitude towards vaccination, with only 3 (5.4%) respondents expressing opposition to vaccination, and just one of them believing that opinions won't change in the future.

Medical professionals, particularly doctors, continue to be the most influential and reliable source

shaping parental opinions (63.4%). This finding aligns with other studies [3,10,11] which emphasize the pivotal role of healthcare professionals in influencing vaccination decisions for children with disabilities [13].

Patient organizations, essential for educating families dealing with rare diseases like SB, also play a significant role in shaping attitudes towards vaccination by providing information and positive experiences from other parents [2].

The study underscores the necessity for further educational efforts among doctors, especially specialists in narrow fields, regarding vaccination in children with neurological disorders, including SB. Additionally, there is a crucial need to raise the awareness among parents and patients, dispelling myths surrounding complications and negative consequences of vaccination.

A limitation of this study lies in its reliance on parental responses, and not all parents agreed to participate in the questionnaire. A more extensive survey involving a larger number of parents and comprehensive input from healthcare professionals could offer a deeper understanding of the situation and the reasons for low vaccination coverage among children with SB in Ukraine.

## Conclusions

The study reveals a low vaccination coverage among children with SB in Ukraine (12.5% fullyvaccinated children and 51.8% completely unvaccinated), significantly lower than the general Ukrainian population's vaccination coverage, despite sufficient knowledge about vaccines and their importance. The crucial role of healthcare professionals, especially specialists, in informing parents about the vaccinations necessity highlights the importance of increasing knowledge across all medical fields, strengthening public awareness, and providing education within patient groups to enhance immunization coverage and protect children with SB against preventable infectious diseases.

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