

# Consumer Perspectives on Pediatric Rheumatology Care and Service Delivery

## A Qualitative Study

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**Objectives:** This study aimed to elicit parental and adolescent perspectives on pediatric rheumatology care and service delivery and to describe the impact of this process on a proposed model of care addressing pediatric rheumatology service delivery.

**Methods:** Adolescents with juvenile idiopathic arthritis (JIA) and caregivers in New South Wales, Australia, participated in focus groups or semistructured interviews conducted from August to November 2011. Transcripts were coded and thematically analyzed. Changes to the model of care as a result of this process were identified.

**Results:** Thirty-seven parents and 13 adolescents participated. Five main themes were identified including (1) optimize service efficiency (promoting awareness about JIA, minimizing delays in diagnosis and treatment, continuity of care, holistic and integrated care, access to health care providers with JIA expertise, extending pharmacy services, regional outreach programs); (2) transitional care (trust and rapport with the adult rheumatologist, comprehensive information transfer of patient history); (3) psychosocial support (social and financial aid, mental health services, vocational guidance, peer support); (4) informational needs (medicine adverse effects, nutritional guidance, pain management, administering medications, obtaining medical equipment); and (5) school-based support and advocacy (to promote acceptance, provide academic assistance, facilitate environmental modifications, offer alternative activities). The model of care was extended to include consumer-focused concerns.

**Conclusions:** A well-coordinated network of services, timely and accurate information about the illness, treatment and support services, adequate pharmacy support, and school-based advocacy are proposed to be needed to ensure pediatric rheumatology services that are accessible and responsive to the needs of patients and their families.

**Key Words:** health services research, qualitative research, pediatric rheumatology, adolescent

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Consumer input in the planning of health services is widely advocated to improve the quality of health care.<sup>1–3</sup> In the United Kingdom and Australia, consumer involvement in service development is a policy requirement.<sup>4</sup> The opportunities for consumer involvement in service development remain limited because of resource constraints and uncertainty about how to achieve effective consumer involvement.<sup>1,2</sup>

Responding to the needs of people with chronic disease remains an important challenge, but their experiential knowledge of illness can provide relevant information to improve service delivery.<sup>5,6</sup> Juvenile idiopathic arthritis (JIA) is the most common rheumatic disease of childhood; it has a prevalence of 1 to 4 per 1000 children younger than 16 years.<sup>7</sup> Children and adolescents with JIA can experience severe pain, disability, and poor psychosocial outcomes.<sup>8–13</sup> Management of JIA involves pharmacological interventions, physiotherapy, occupational therapy, and psychosocial support.<sup>11,12,14,15</sup> Ready access to appropriate care is needed to improve outcomes in JIA, yet evidence suggests that poor access to optimal care remains a crucial problem worldwide.<sup>16</sup>

Consumer input can help facilitate service delivery that is relevant to the needs of patients and their families. This is likely to enhance the accessibility and acceptability of pediatric rheumatology services to improve health care delivery, patient satisfaction, and health outcomes. Existing studies have focused on interventions such as psychoeducational programs<sup>17</sup> or a specific aspect of care including communication with doctors,<sup>18</sup> occupational therapy,<sup>19</sup> and transitional care.<sup>20–22</sup> However, consumer perspectives on the broader aspects of service delivery in pediatric rheumatology are lacking. This study aimed to elicit parental and adolescent perspectives from this perspective and to describe the impact of this process on a proposed model of care developed as a framework for the way pediatric rheumatology health services are to be delivered.

## METHODS

### Context

There has been concern that current pediatric rheumatology services in New South Wales (Australia) lag behind best practice models of care as described in international literature and other jurisdictions across Australia. In response, the NSW Agency for Clinical Innovation Musculoskeletal Network developed and proposed a model of care for pediatric rheumatic conditions to guide and support the accelerated implementation of clinical services in the state of New South Wales, Australia. The model of care has been developed by a panel of health care professionals, consumers, and consumer advocates with the core aim of ensuring that children and adolescents who live in New South Wales will have access to timely and appropriate diagnosis and comprehensive management of rheumatic diseases.

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This model of care concentrates on the provision of multidisciplinary team care in tertiary centers, outreach to rural and regional areas, transition care to adult services, and health education of patients, families, and medical professionals concerning pediatric rheumatology conditions.

## Participants

Participants were recruited through Arthritis NSW, The Sydney Children's Hospital Network, and The John Hunter Children's Hospital, Newcastle, and pediatric rheumatologists' private practices. They were purposively selected from patient databases at each recruiting site to achieve a range of age, gender, geographical location, time since diagnosis of JIA their disease, and symptom severity. Participants were eligible if they were adolescents 14 years or older diagnosed with a JIA, or parents/caregivers of children or adolescents with JIA. Also, participants had to be English speaking and able to give informed consent. After approval was obtained from the Sydney Children's Hospital Network Human Research Ethics Committee, participants were invited to participate either face-to-face, by telephone, or by an invitation letter sent by Arthritis NSW.

## Data Collection

We developed a list of preliminary questions from a literature review and discussion among the research team. The question guides are provided in Supplementary Data 1 (available online at <http://links.lww.com/RHU/A29>). The question guides addressed 3 topics: general experiences of living with JIA, experiences of current health care services, and perspectives on the proposed model of care.

Initially, the participants were invited to participate in 1 of 4 scheduled focus groups between August and November 2011. However, if they were unable to attend, participants were given the option to participate in a semistructured interview in a hospital meeting room or alternative place at the participant's convenience. Both focus groups and interviews are useful for gaining insight into people's experiences of illness and of health services.<sup>23</sup> The 2-hour focus groups were convened in the NSW Arthritis meeting room or another centrally located meeting room. The focus groups were facilitated by A.T., who had no contact with the participants before the study. An observer (J.J.) recorded field notes on group dynamics and interactions and context surrounding the discussion. A.T. conducted semistructured individual qualitative interviews either face-to-face or by telephone, according to the participant's preference. All focus groups and interviews were audio recorded and transcribed verbatim. Data collection ceased when theoretical saturation was reached.

## Data Analysis

The transcripts were entered into HyperRESEARCH (3.0; Researchware Inc, Randolph, Mass), a software package for storing, coding, and searching qualitative data. Drawing on thematic analysis, the transcripts were reviewed line-by-line by A.T./J.J., who inductively and independently searched for concepts and identified themes relevant to consumer perspectives on pediatric rheumatology care and service delivery. A.T. refined the coding structure until it captured all relevant concepts. To enhance the analytical framework and potential for offering meaningful insight, A.T. discussed the preliminary themes with the research team.

To assess the impact of this process on the proposed model of care, D.S.-G./A.T. discussed and identified changes to be considered for the final model of care.

## RESULTS

Of the 50 participants, 37 (74%) were parents, and 13 (26%) were adolescents diagnosed with JIA. The participant characteristics are provided in Table 1. Participants ranged in age from 14 to 66 years. Four focus groups (with  $n = 4$ ,  $n = 4$ ,  $n = 9$ ,  $n = 10$  participants, respectively), 4 telephone, and 6 face-to-face interviews were conducted with parents. Four face-to-face and 9 telephone interviews were conducted with adolescents. An adolescent focus group could not be convened because of lack of response and competing commitments.

Five main themes relating to consumer perspectives on pediatric rheumatology services were identified. These included (1) optimize service efficiency (to promote general awareness about JIA, minimize delays in diagnosis and treatment, provide continuity of care, coordinate holistic and integrated care, ensure access to health care providers with JIA expertise, extend pharmacy services, provide regional outreach programs); (2) transitional care (to build trust and rapport with the adult rheumatologist, ensure comprehensive information transfer of patient history); (3) psychosocial support (social and financial aid, mental health services, vocational guidance, peer support); (4) informational needs (medicine adverse effects, nutritional guidance, pain management, administering medications, obtaining medical equipment); and (5) school-based support and advocacy (to promote acceptance, provide academic assistance, facilitate environmental modifications, offer alternative activities). A summary of these themes is provided in the Figure 1.

### Optimize Service Efficiency

#### Promote General Awareness About JIA

Many participants strongly believed that there was a lack of knowledge and understanding about JIA among health care providers including general practitioners and pediatricians. In particular, they were frustrated about a perceived unwillingness or inability of primary care providers to treat intercurrent illnesses or symptoms in children with JIA. For families, this meant additional time and costs were needed to access specialist pediatric rheumatology services. A general lack of awareness was also believed by participants to be a major cause of delays in the diagnosis of JIA.

#### Minimize Delays in Diagnosis and Treatment

Delays in diagnosis caused anxiety among participants. They felt that better diagnostic algorithms and tests were needed to facilitate timely diagnosis. Some parents also recognized the critical shortage of pediatric rheumatologists, which they attributed to the delays in diagnosis of JIA. They suggested more awareness about JIA among primary health care providers was urgently needed.

#### Provide Continuity of Care

The participants valued familiarity and felt reassured when they received continuity of care. They anticipated this would prevent confusion if they were to receive contradictory advice particularly about medications.

#### Coordinate Holistic and Integrated Care

To improve the quality of service delivery and patient experience, the participants suggested "combined" clinics, which would include rheumatology, physiotherapy, and ophthalmology and educational, psychological, and social services. They believed that more efficient information exchange, regarding the patient's history and health status, was needed between

**TABLE 1.** Participant Characteristics (n = 50)

Characteristic	n	Percentage of All Participants
Parent/carer participants (n = 37)		
Father	8	16
Mother	29	58
Participant age, y		
20–29	2	4
30–39	7	14
40–49	24	48
50–59	4	8
Marital status		
Single	2	4
Married/de facto	32	64
Separated/divorced	3	6
Highest level of education		
High school	11	22
Tertiary	26	52
Employment status		
Not employed (homemaker)	10	20
Part time or casual	10	20
Full time	17	34
Location of residence		
Metropolitan	21	42
Regional	16	32
Age of child diagnosed with JIA, y		
0–5	9	18
6–10	8	16
11–15	15	30
>15	5	10
Time since child's diagnosis, y		
<5	19	38
5–10	11	22
>10	7	14
No. children		
1	3	6
2	18	36
3	13	26
>3	3	6
Adolescent participants (n = 13)		
Gender		
Male	4	8
Female	9	18
Age, y		
14–15	7	14
16–17	3	6
18–19	1	2
>19	2	4
Employment status		
Student	12	24
Part time or casual	1	2
Location of residence		
Metropolitan	8	16
Regional	5	10

**TABLE 1.** (Continued)

Characteristic	n	Percentage of All Participants
Time since diagnosis, y		
<5	5	10
5–10	2	4
>10	6	12

medical specialties and allied health services. To coordinate and promote a network of services, parents suggested forums, printed resource packs, Web sites, and active dissemination of information about services in rheumatology or primary care clinics. This would enable parents to feel better equipped to access relevant services in a timely manner.

### Ensure Access to Health Care Providers With JIA Expertise

The participants felt they needed to have ready access to health care providers who could give advice about JIA, medications, and pain management. This would offer reassurance and enable them to respond to unexpected complications and any adverse reactions to the medications. Participants felt they should be able to seek advice from the pediatric rheumatologist or specialist nurse by phone call or e-mail and avoid unnecessary visits to the emergency department where the child may be exposed to infections.

### Extend Pharmacy Services

Parents expressed exasperation with pharmacy services as some parents were outrightly refused supply of syringes to administer their child's arthritis drug injections. A few reported adversarial encounters when trying to defend themselves from suspicion they perceived pharmacists held toward them. They also found it problematic to obtain a sharps container and felt this should be automatically provided by the pharmacist.

### Provide Regional Outreach Programs

Participants felt that regional services would reduce the travelling time and cost for families living in regional areas. Families could spend more time doing "normal things." However, some indicated a preference to access high-quality specialist care despite the time and costs required.

### Transitional Care

#### Build Trust and Rapport

Many parents and adolescents felt that building trust and rapport with adult rheumatologist was needed. During transition, they wanted to retain contact with their pediatric rheumatologist for reassurance, particularly if changes to the treatment regimen posttransfer were required. A few parents believed that adolescents should be involved in deciding when to transfer to adult rheumatology services.

#### Ensure Comprehensive Information Transfer

Parents suggested that a complete and comprehensive patient history should be provided to the new rheumatologist. Participants felt parents should not have to be depended on to relay their child's medical history.

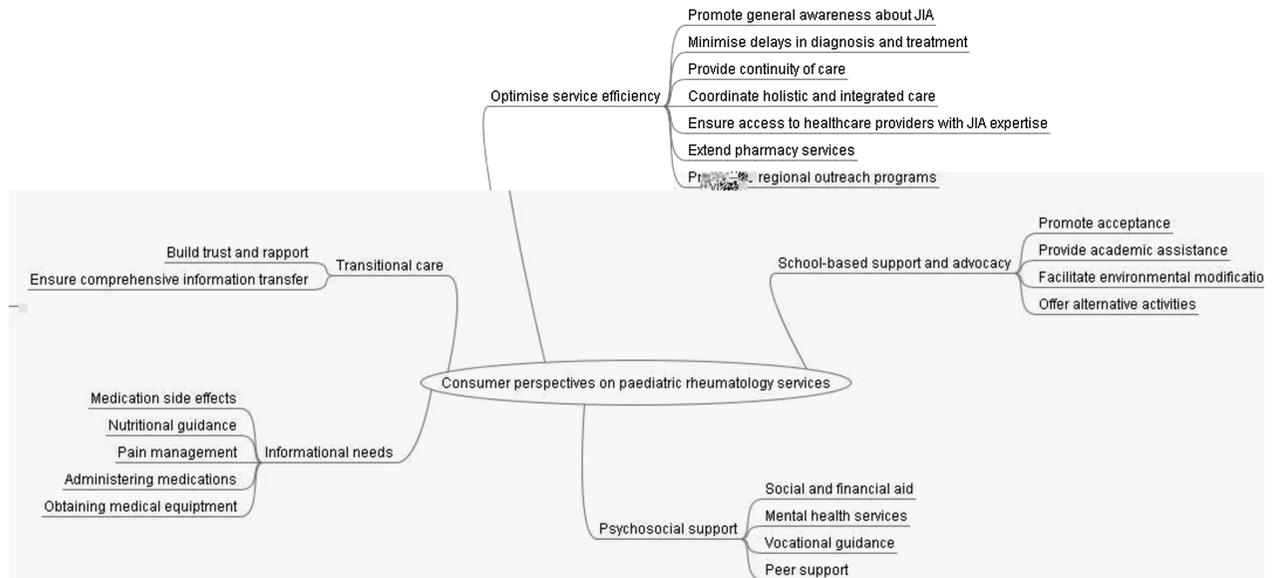


FIGURE. Thematic schema of consumer perspectives on pediatric rheumatology services.

## Psychosocial Support

### Social and Financial Aid

Parents emphasized the need for immediate information and practical assistance to access entitlements relating to medications, travel costs, parking (including disability parking permits), accommodation, and social security allowances to help with medications and care. Some perceived it was unfair to only inadvertently learn of the benefits from other families or Web sites as they could have benefited from receiving the information sooner. Participants strongly believed that all parents should be given this information more “formally” immediately after diagnosis. Also, a few suggested more assistance be available to complete insurance forms.

### Mental Health Services

Most participants believed that psychological services were vital to address chronic pain and depression, mood and aggression related to steroid use, low self-esteem in patients, sibling support, and family functioning. Parents felt overwhelmed and helpless, particularly when their child experienced severe depression and emphasized the importance of psychological intervention.

### Vocational Guidance

For older adolescents, there was concern about the perceived limited job opportunities and stigmatization by employers. They believed careers advice would be beneficial for young adolescents with JIA pursuing work opportunities. Some adolescents struggled with finding a job because of the pain and physical limitations and were conflicted about disclosing their disease to prospective employers.

### Peer Support

Almost all participants believed that they needed peer support to share experiences and coping strategies and reduce their sense of isolation. Many urged for social events such as

campus that would provide an opportunity for both patients and their families to build positive supportive relationships.

## Informational Needs

### Medication Adverse Effects

Many participants expressed uncertainty and anxiety about potential adverse effects associated with medications. They speculated whether any developmental delays or physical symptoms were caused by the medications. Most felt they needed more information about medications, particularly about potential complications and adverse effects.

### Nutritional Guidance

Some parents wanted information about whether dietary interventions could be recommended to reduce the severity of JIA. A few expressed they had tried various diets and supplements to minimize the chance of flares of disease that were not part of their child’s rheumatologist’s recommendations.

### Pain Management

Participants discussed various techniques for pain management. Both parents and adolescents described feelings of helplessness and overwhelming distress when they felt unable to control the pain. They believed it was important to receive more information on a wider range of pharmacological, lifestyle, and practical methods to minimize pain.

### Administering Medications

Giving their child injections was deemed by some parents to be the most distressing aspect in caring for a child diagnosed with JIA. One mother expressed that she had not been trained by a health care professional on how to give an injection. Adequate training and support for injecting medications were suggested.

### Obtaining Medical Equipment

Some parents expressed frustration about the difficulties and lack of information on obtaining wheelchairs or walking

aides for their child. They were unsure about where to obtain the equipment and found it onerous to search for information about the costs and suitability of wheelchairs for their child. More information about obtaining medical equipment was suggested.

## School-Based Support and Advocacy

### Promote Acceptance

Some parents received support from their child's school. For example, they reported that the school arranged for the child's classes to be held in ground-floor classrooms or permitted extra time for their child to get to their next class. On the other hand, a number of participants felt that schools lacked compassion and understanding about the needs of children with JIA. They expressed that teachers did not understand their child's pain, fatigue, and physical limitations and reported that teachers mistook this as misbehavior and reprimanded their child. The unpredictable and fluctuating severity of the symptoms, they believed, made it even more difficult for teachers to understand the nature of the disease. Some adolescents experienced bullying, a harrowing sense of isolation, and "being different" from other students. The participants suggested that a health professional could educate teachers and students about JIA, to promote understanding and consideration of the needs of children with JIA.

### Provide Academic Assistance

Some children had a teacher's aide to assist with school work, and this was appreciated by the participants. A few participants believed that children also needed assistance with activities requiring physical strength and movement such as woodwork and sport.

### Facilitate Environmental Modifications

Some parents of children with physical and mobility limitations identified modifications needed in the school. These included wheelchair ramps and lever-style bathroom taps. However, a few felt frustrated when their attempts to achieve this were unsuccessful.

### Offer Alternative Activities

Participants felt that alternative school outings should be organized for children with JIA, to minimize the child's disappointment and feelings of being ostracized.

### Impact on Model of Care Development

The children's and families' experiences confirmed the existing concerns regarding the paucity and quality of current services such as poor access to care, delays in diagnosis, and lack of interdisciplinary care. Consumers identified areas including interdisciplinary care (combined clinics with ophthalmology especially for patients with uveitis), need for active dissemination of information (Web site for families and health professionals, formalized written information), and better coordination and information exchange with pharmacy services (advocacy for easy access to needles, syringes and sharps bins as is available for patients with diabetes mellitus). Consumers also urged for increased awareness of JIA in the community. As a result of consumer consultation, the proposed model of care was adjusted by the Musculoskeletal Network Pediatric Rheumatology Working Group. The role of the community

pharmacist was added, suggestions for the dissemination of information and promoting access to services were augmented, and experiential data were incorporated to emphasize aspects of service delivery deemed important by consumers (Table 2 is available online only at <http://links.lww.com/RHU/A30>).

## DISCUSSION

Patients with JIA and their caregivers identified 5 major areas to address in pediatric rheumatology care and service delivery including optimizing service efficiency, providing transitional care, offering adequate psychosocial support, meeting information needs, and improving school-based support and advocacy. To improve service efficiency, they urged for better awareness about JIA among health care providers, implementation of strategies to minimize the delays in diagnosis and treatment of JIA, continuity of care, enhanced coordination of holistic care, ready access to health care providers with JIA expertise, improved community pharmacy services, and additional regional JIA clinics. They also emphasized the importance of psychosocial support to address social and financial difficulties, mental health problems, vocational limitations, and sense of isolation. School-based support and advocacy were deemed critical to promote optimal psychological, social, and academic outcomes in children with JIA.

Parental perspectives encompassed a broader range of issues relating to pediatric rheumatology care and service delivery, which had not been previously identified in the model of care. These included a perceived lack of adequate pharmacy services, social and financial aid, and logistical support to obtain medical equipment. In comparison, the adolescent respondents were more focused on the impact of juvenile arthritis on their self-concept, social life, education, and vocational opportunities. More specifically, adolescents emphasized the need for access to specialist care, ability to engage in normal activities, reassurance in clinical environments, psychological support to improve their confidence, peer interaction, school advocacy, and information about medications, pain management, and medical advances.

Our findings also demonstrate that consumer perspectives can have an impact in the planning of service delivery in pediatric rheumatology. In addition to validating the concerns recognized by health care organizations, namely, the paucity and quality of services, consumers were able to identify several important and underrecognized service delivery needs including interdisciplinary care particularly with ophthalmology services, active dissemination of information for consumers and health care providers, and better coordination with community pharmacy services.

However, our study has a number of limitations. We did not conduct serial interviews or focus groups over time with the same participants to ascertain how experiences and perspectives may have changed over time. Although conducting interviews and focus groups achieved methods triangulation, difficulties in drawing in-depth information were noted in conducting telephone interviews with adolescents. Nonverbal prompts and visual cues during face-to-face interviews facilitated more careful and exhaustive dialogue with adolescents. Non-English-speaking people were excluded, and some individuals did not attend focus groups or interviews because of competing commitments and priorities. Therefore, the transferability of our findings may be limited.

Our findings share some similarities with previous studies on consumer perspectives on various aspects of care. Studies have found that young people with JIA and their parents need psychosocial, education, and vocational support services;

information about JIA progression, treatment, and pain management; and continuity of care.<sup>17,18,24,25</sup> Opportunities to meet other young people with JIA and their families have also been suggested to reduce sense of isolation. Vocational support has been reported to be either lacking or unresponsive to the needs of young people with JIA.<sup>26,27</sup> In transition to adult rheumatology care, ability to trust the specialist has also been emphasized.<sup>24</sup>

However, our study highlights a number of areas in pediatric rheumatology care and service delivery deemed important by adolescents with JIA and their caregivers that have received little attention in the literature. To facilitate access to relevant health care services, adolescents and caregivers emphasized the value of coordinated holistic care combining specialist rheumatology, physiotherapy, occupational therapy, nursing, ophthalmology, pharmacy, and social and psychological support services. This is particularly vital as JIA and the treatments used are associated with various complications involving multiple systems and organs of the body. In addition, they suggested that the integrated network of services could be promoted through family information forums, resource packs, support groups, Web sites, and pediatric rheumatology clinics. Adolescents and caregivers also believed that core pediatric rheumatology services should include timely and formal provision of information relating to the disease, treatment, financial entitlements, and practical assistance (including disability parking permits, acquiring wheelchairs or walking aides); adequate community pharmacy support to obtain syringes and sharps containers; and involvement of health care professionals in providing school-based advocacy for young people with JIA.

Ongoing research is needed to evaluate the feasibility and implementation of various aspects in the model of care. Health service research can be used to assess the effectiveness of health care practices and organization of care on consumer satisfaction, quality of health, and health outcomes. However, the development of health service interventions is challenging and arguably more complex compared with drug or surgical trials.<sup>28</sup> It has been recommended that health service activities should be regarded as a complex intervention,<sup>29</sup> which are “built up from a number of components, which may act both independently and interdependently.”<sup>30,31</sup> This can ensure adequate development and piloting and appropriate consideration of practical issues of implementation.<sup>32</sup> The unique methodological challenges are attributable to the “number of and interactions between components within the experimental and control interventions, number and difficulty of behaviors required by those delivering or receiving the intervention, number of groups or organizational levels targeted by the intervention, number and variability of outcomes, and the degree of flexibility or tailoring of the intervention permitted.”<sup>31</sup> Most health service intervention trials in rheumatology have focused on the adult patient and do not use a framework for complex interventions.<sup>33–36</sup> A randomized controlled trial of a pragmatic occupational therapy program on self-management and health status among adult patients with early rheumatoid arthritis found that self-management improved, but not health status. However, lack of numbers in the intervention group used self-management sufficiently to make a difference and suggested that occupational therapy should be evaluated as a complex intervention with programs developed from a theoretical and evidence base.<sup>37</sup> In 2008, the Medical Research Council published guidance on the development, evaluation, and implementation of complex interventions to improve health.<sup>32</sup> We recommend that future studies, for example, to assess pediatric rheumatology educational interventions, integrated services, transition, regional

outreach programs, pharmacy services, and school-based advocacy programs, use this framework for the development of trials for complex interventions.

We have demonstrated that consumers can articulate a range of issues relevant to pediatric rheumatology care and service delivery and suggest how they can be incorporated in the development of service delivery models. Health care professionals and organizations should endeavor to involve consumers in health service development. This can help to ensure that services are accessible and responsive to the needs and concerns of patients and their families.

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