



*Arthritis Queensland*

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# Family survey report

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Survey findings to inform action planning for Juvenile Idiopathic Arthritis

*July 2012*

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*Good thinking*



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# Background

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To inform a state-wide action planning process, Arthritis Queensland commissioned a survey of families of children with juvenile idiopathic arthritis in July 2012. The survey tool and process was approved by the PA Hospital Ethics Committee.

The survey aimed to gain input from families who are experiencing juvenile arthritis to ensure action planning responded to the issues and needs faced by these families and their children. Surveys of health professionals and education support providers were undertaken at the same time and will be reported separately.

Surveys were distributed to more than 200 families listed in databases held by the following organisations:

- Arthritis Queensland (149 surveys sent)
- Montrose (54 surveys sent)
- Services for Australian Rural and Remote Allied Health - SARRAH (approximately 55 surveys sent)
- Dr Navid Adib (up to 30 surveys distributed).

Surveys were sent by email where possible, with a link to an online survey. Where email addresses were not known, a hard copy version of the survey was sent by mail.

73 responses were received by 2 August 2012. A number of respondents have more than one child with juvenile arthritis, so responses relate to 78 children in total. It is estimated that between 875 and 3,500 children in Queensland have juvenile arthritis. Survey participation represents 2% to 8% of these.

While every effort was made to reach as many families as possible, distribution of the surveys was limited to people already connected with the supports offered by Arthritis Queensland, Montrose Access and SARRAH.

This report presents the results of that survey. Not all respondents answered all questions - the report analyses responses from those who answered the question. Results are generally presented as percentages of the total respondents to the question under discussion.

# Main findings

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The report highlights several major issues confronting children with juvenile arthritis and their families.

These can be summarised as follows:

**1. Lack of awareness of the disease in the community and among health and education professionals.**

This lack of awareness contributes to delays in achieving diagnoses for children, many of who are in serious pain while they wait. 47% of families reported waiting more than six months to find out what was wrong with their child.

Lack of awareness is also a significant issue once children reach school age, with parents reporting a general lack of understanding among teachers and other education stakeholders.

**2. Lack of access to services**

Queensland has one paediatric rheumatologist, and a small number of other specialists with an understanding of juvenile arthritis. Families from regional and remote areas of Queensland find it particularly difficult to access specialist help and the ancillary services like physiotherapy and hydrotherapy that many find helpful.

**3. The financial burden of juvenile arthritis**

Many families reported a significant struggle financially to meet the cost of specialist appointments, medications, allied health treatments, travel to access specialist help and even basics like heating and hot water to ease their child's pain. Some parents are paying out of pocket for medications that they do not qualify for under the PBS. 25% of families said that cost had stopped them from accessing services for their child, while the remainder talked of the significant sacrifices they make to pay for treatment for their children.

**4. A need for emotional support and connection**

Families talked about feeling alone, and their child feeling "different". Many called for support networks, camps and activities for children and families so they could meet others in the same situation.

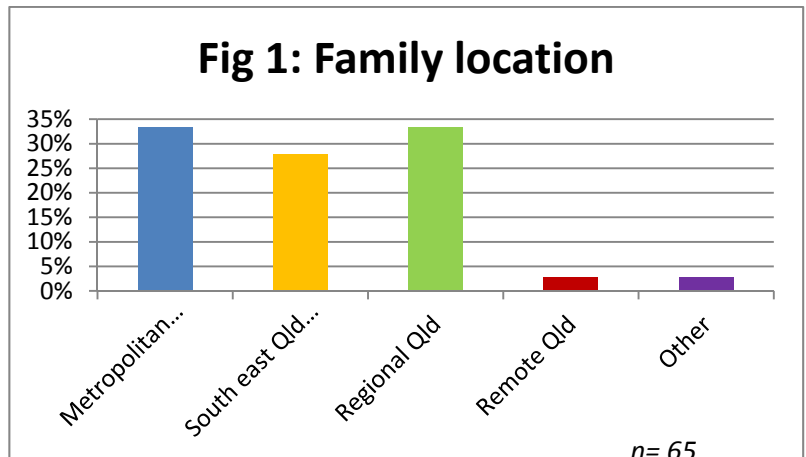
**5. Better information resources for parents**

A number of parents suggested developing information kits or resources for families with a diagnosis of juvenile arthritis to help them navigate the system and understand the disease and treatment options.

# Respondent profile

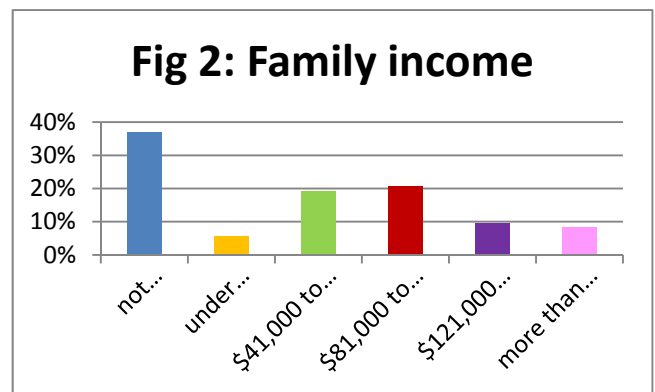
## Family location

Survey respondents were from a range of locations, including regional and remote Queensland as shown in Figure 1. This allows some comparison between the experiences of metropolitan and regional families later in the report.



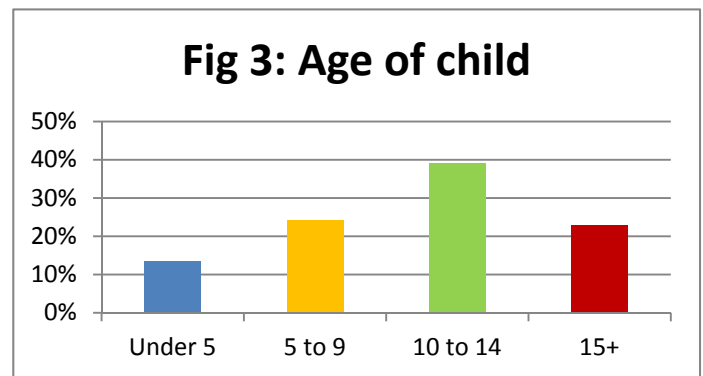
## Family income

Incomes also varied, with many respondents opting not to disclose this information. Among those people who did answer this question, many earned above average family incomes.



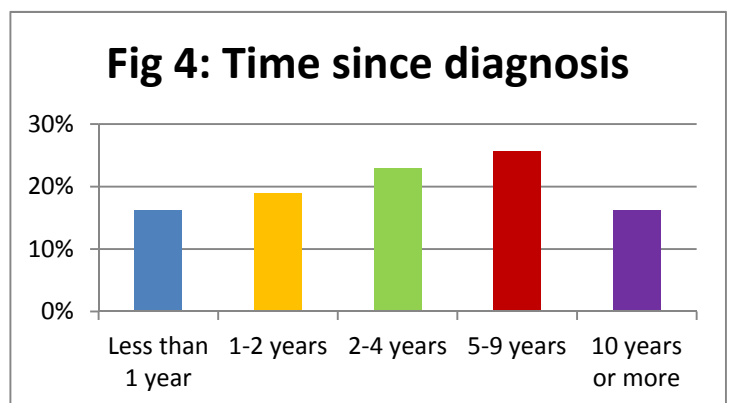
## Family makeup

The most common family size was two children (33 respondents) and three children (21 respondents). 13 families had four or more children.



Only four respondents reported having more than one child with juvenile arthritis - three families had two children with juvenile arthritis and one family had three children with juvenile arthritis. For most questions, families responded about a total of 71 children including those from families with more than one child with juvenile arthritis. The majority of respondents had children over the age of 10, as shown in Figure 3. This allows an analysis of differences in experiences for families with younger children later in this report.

There was a good cross-section from recently diagnosed children to those who had been diagnosed ten years or more ago, providing insights from a range of perspectives throughout the survey responses.



## Severity

Respondents were evenly split in terms of the extent of their child's arthritis, with 51% affected in four joints or fewer currently and 49% affected in five joints or more.

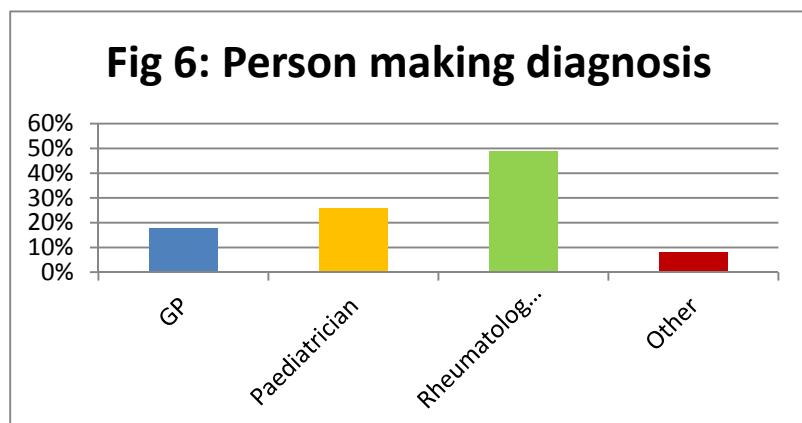
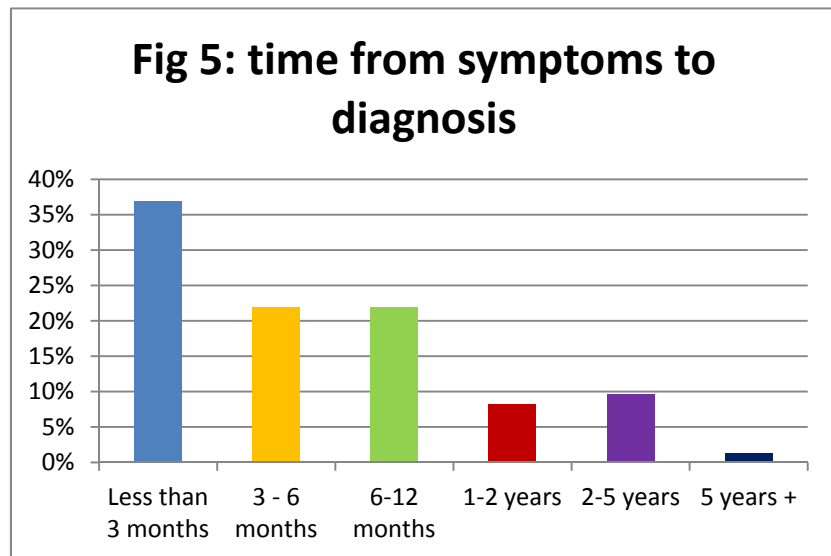
# Diagnosis experience

The most common time reported from the onset of symptoms to a diagnosis of juvenile arthritis was less than three months (37% of children), with 81% of children diagnosed in less than 12 months.

The time taken from symptoms to diagnosis did not seem to relate to the length of time since diagnosis, indicating that there may not have been significant change over

time in the speed with which people are diagnosed. There also seemed to be little relationship between distance from specialist services and the time it took to have a diagnosis, with families in Brisbane somewhat over-represented among those who took a year or more to be diagnosed (45.5% of these children were from Brisbane although only 33.9% of respondents were from Brisbane).

Most families learned of their child's diagnosis from a rheumatologist, with GPs and paediatricians the other specialists involved. "Other" responses were "all of the above", "orthopaedic surgeon" (2 families) and "Me - I insisted on an MRI".



Of those diagnosed by a GP, 5 families were from metro Brisbane, 6 from south east Queensland and 2 from regional Queensland.

## Comments about diagnosis

Survey respondents were asked to comment about the experience of diagnosis. The most common comment related to the lack of knowledge among GPs, paediatricians and physiotherapists about juvenile arthritis.

"There are not enough doctors (GPs) with knowledge of JIA. If there had been our heart ache during the first 5 months may have been less."

The next most common theme was about the stress, fear and frustration involved in the process of finding the right diagnosis. People who waited twelve months or more for a



diagnosis were most critical, often reporting that doctors didn't listen to them or take their child's issues seriously, or misdiagnosed their child's condition.

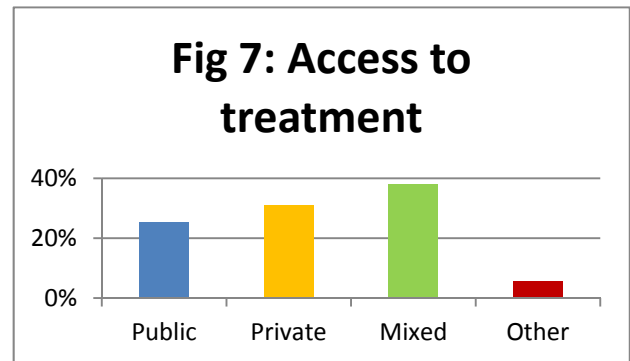
Three respondents commented that it was hard to get into specialists, and two noted a lack of specialists in regional areas.

"In regional Queensland it was going to take 4 months to see the rheumatologist. We chose to fly to Brisbane. He gave us the diagnosis."

# Treatment

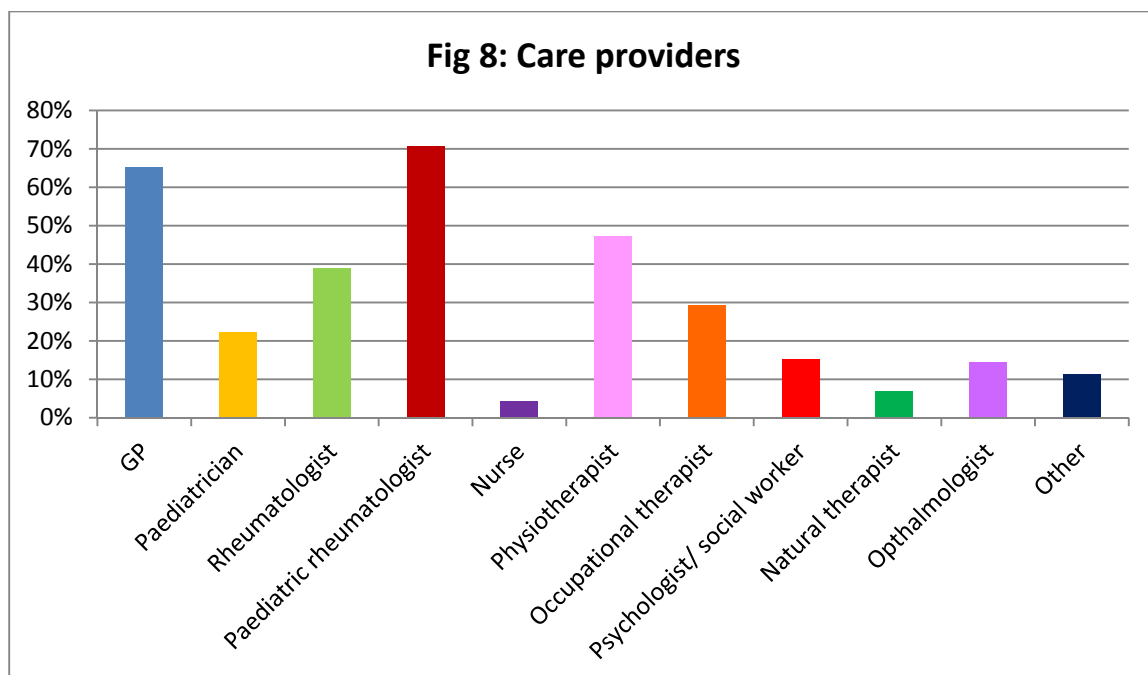
The most common way families accessed treatment was a mix of public (free) and private (paid by themselves or their private health insurance), as shown in Figure 7.

Families reported a range of care providers involved in care of their child, with GPs and paediatric rheumatologists involved in the care of more than 65% of all respondents, as shown in Figure 8.

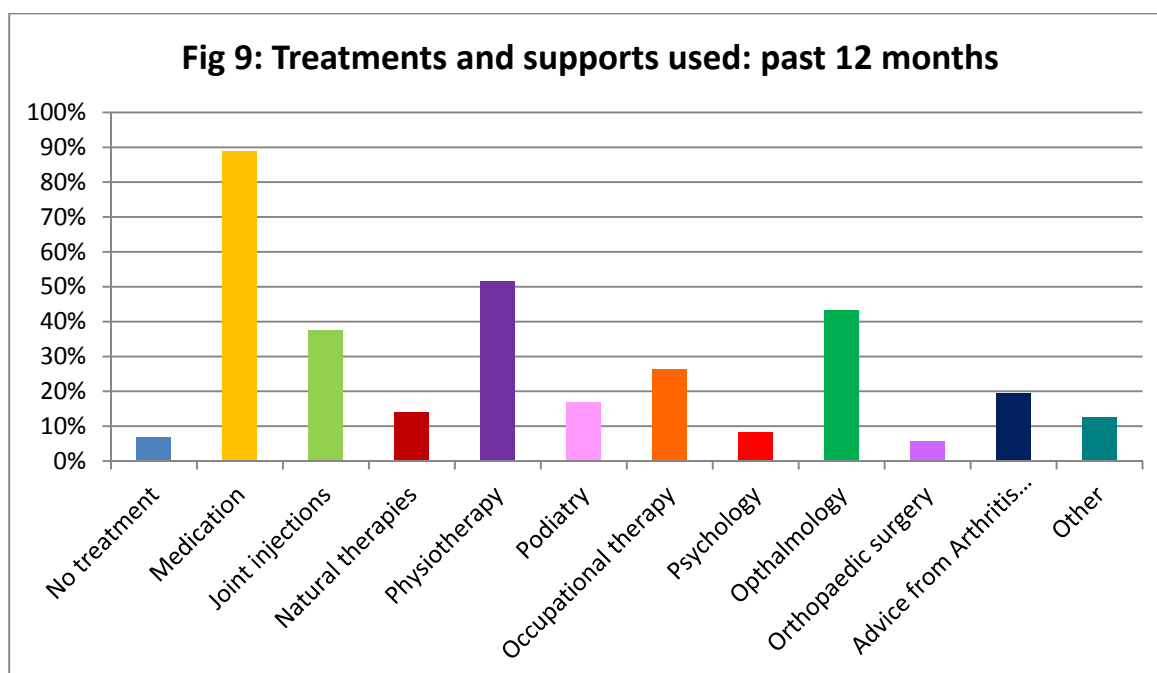


When respondents were asked to nominate the main professional person providing care for their child, responses were as follows:

- Paediatric rheumatologist: 44 respondents
- Rheumatologist: 15 respondents
- GP: 4 respondents
- Natural therapist: 2 respondents
- Paediatrician: 2 respondents



The survey asked families to nominate treatments and supports used by their child or children in the past 12 months. As shown in Figure 9, medication was used by 89% of respondents, with the next most common treatments being physiotherapy (51%) and ophthalmology (43%). Joint injections were named by 38% of families.



For this question, “other” treatments nominated included acupuncture, swimming, osteotherapy, Montrose Access, information from AStretch newsletter, pain management with heat bags, pawpaw cream and neurofen, and a school support worker.

Respondents commented about treatments that had been recommended but that they were not undertaking.

- For those who reported not undertaking treatments that had been recommended:
  - 7 nominated lack of confidence in the treatment as a reason
  - 6 nominated cost as a reason
  - 3 nominated distance
  - For most the reasons related to a child improving or going into remission, concern about side effects, or the child refusing to undertake the treatment
- 14 families reported having been recommended medication but not undertaking this at present - most because it was no longer required, but two because the child refused, three because of lack of confidence in the treatment, two because of distance and two because they did not qualify.
- 13 families reported having been recommended joint injections but not undertaking these at present - most of these because their child is improving or in remission.

### Most effective treatments

Families were asked to nominate the treatments or services that have benefited their child the most. There was wide variation in the responses, with many families nominating a combination of treatments. See Appendix 1 for the full breakdown of responses.

“Medication” was the most common response, either on its own as the single most helpful treatment (14 families) or in combination with other treatments such as exercise, physio, massage, joint injections and/or joint drainage (25 families).

Joint injections were nominated on their own by 5 families, and in combination with other treatments by 14 families.

Montrose Access services were nominated alone by 3 families and in combination by a further 3 families.

### **Satisfaction with services**

Families were asked whether they were satisfied with the level of services their child is receiving or has received in the past. 83% of families were satisfied.

The 17% who were not satisfied referred in their comments to:

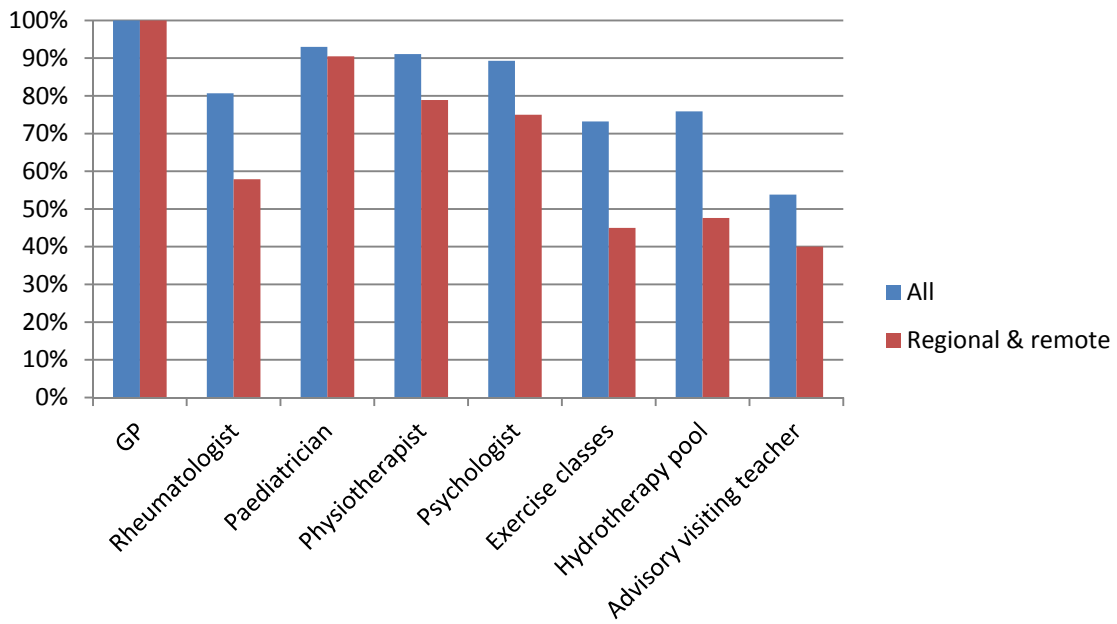
- lack of choice of specialists
- cost of treatment, especially for people who did not qualify for government-subsidised BDMARDS
- distance to services
- the time taken to get a diagnosis
- lack of responsiveness - wait for appointments and information.

### **Access to services**

An issue frequently raised in consultation is access to services outside Brisbane. The survey asked families which services were available within a two hour drive of their home. As Figure 10 shows, services are less likely to be available locally for people living outside south east Queensland. Note that for the last three items - exercise classes, hydrotherapy pool and visiting advisory teacher - up to 45% of respondents replied "I don't know" to this question.

As many respondents noted, a physiotherapist or paediatrician may be available locally but if they are not trained to work with children with juvenile arthritis, parents still need to travel further afield for the right care.

**Fig 10: Services within 2 hours**



# Impact on the child

The majority of families (85%) stated that their child's juvenile arthritis had affected the child's behaviour or personality.

The most common impacts referred to in comments from parents were:

- loss of confidence
- mood swings or moodiness
- lack of participation in activities including sport
- increased fatigue
- withdrawal
- depression.

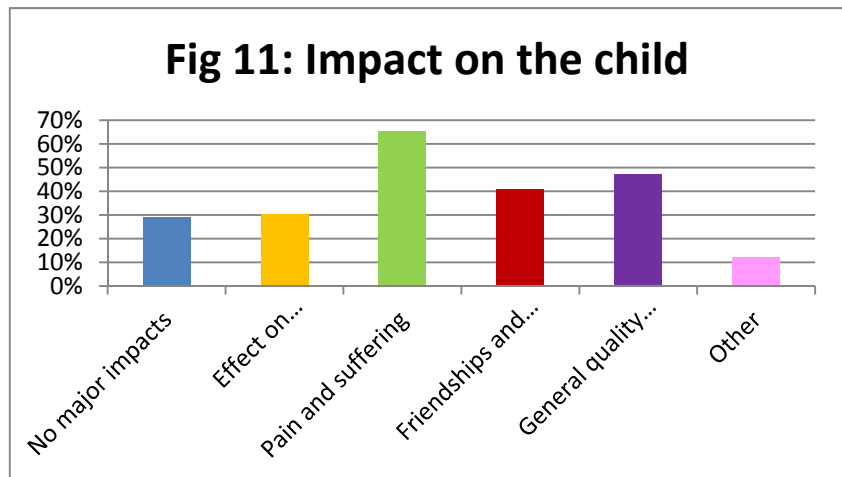
These changes were attributed to the pain from the child's arthritis, the side effects of medication or the negative impacts of being "different".

Two parents were positive, stating that their child's condition had led to them being more mature, resilient and confident.

Families were asked what impact their child's juvenile arthritis had had on the child's life, focusing on the past two years.

The most common response was significant levels of pain and suffering (65%) as shown in Figure 11.

The "other" responses related to the reduction in children's ability to participate in sport.



Parents spoke of the condition completely changing their child's life.

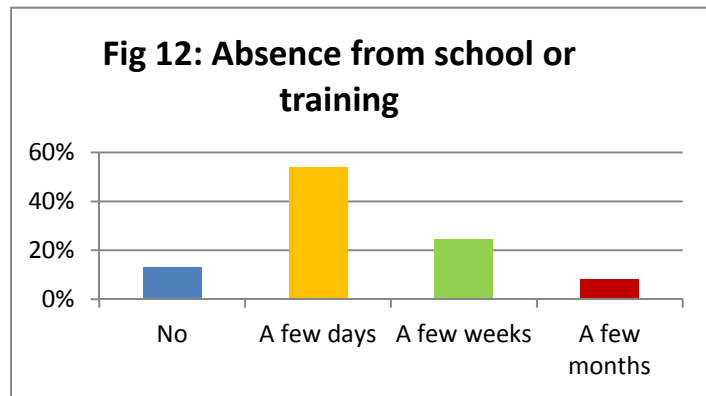
"He is unable to be a normal child and run amuck. He has experienced pain and discomfort most adults haven't."

"I wish there was more awareness of the disease so he did not feel like the odd child out all the time."

"I feel so helpless that we cannot help her."

## Impact on education

87% of families who had a child in school, college or training reported that their child had missed some school in the past 12 months because of juvenile arthritis. As shown in Figure 9, 54% of families reported their child missing a few days, mostly to attend appointments. Those who missed more than a few days usually referred to pain from flare ups.



Comments included:

“My youngest has missed days and now has missed vital learning...”

“He misses a few days every term to visit specialists in Brisbane. The specialists work on different days so we are unable to condense his visits to one day...”

The major impacts on children’s education and learning outcomes from juvenile arthritis that families reported were:

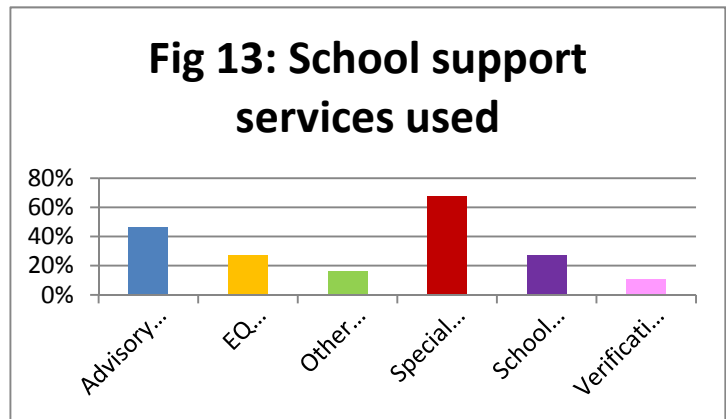
- inability to participate in sport or PE
- falling behind academically due to absence from school
- difficulties with writing
- reduced ability to concentrate.

### Education support services

35 families answered a question about support services they had used to help with school.

Special needs teachers and Advisory Visiting Teachers were the most common supports used.

When asked what support would help their child at school when they were in pain or flare up, 55% of families said that existing support was fine, while 43% stated that more could be done.



The main suggestion families had to improve support at school was better education of teachers, school nurses, other students and the general community. The next most common request was for more empathy and emotional support from school staff. Communication between Advisory Visiting Teachers and classroom teachers was also raised as an area for improvement.

“More understanding when he complains of pain. Some teachers do not believe him.”

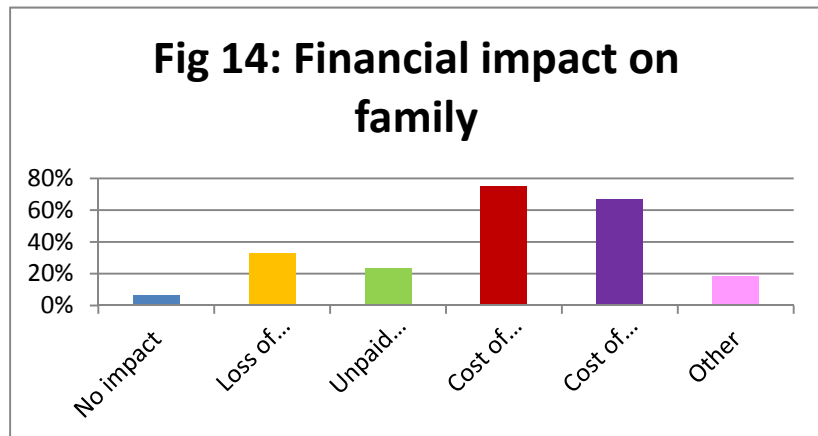
“Educating classroom teachers, PE teachers, local/ regional physiotherapists and school nurses about JIA.”



# Impact on families

## Financial impact

Almost all respondents (94%) reported that their child's condition had affected the family's finances in a range of ways as shown in Figure 14. The most common impacts related to the cost of cost of health services and medications.



"Other" costs included heating, hot water, home modifications and, for families from regional areas, the costs associated with travel to see specialists.

"The financial impact is HUGE! Trips to Brisbane include petrol, food, accommodation, appointment fee, parking fee and parent to use up their sick leave. Partner this with medication, doctor visits, medicine (antibiotics and cough medicine when they get sick due to immunosuppressant meds) and cost of running air conditioning (heating) every night during winter."

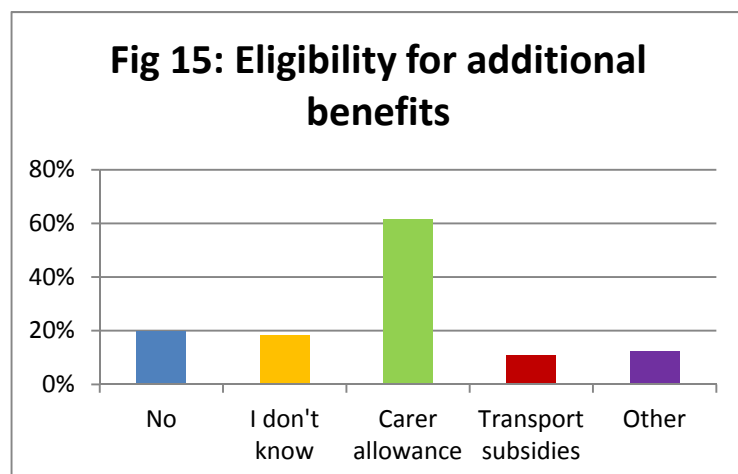
"Injections are \$550 per fortnight"

While three quarters of respondents reported that their financial circumstances had not had an effect on the treatment their child had been able to access, this was not without impact on the family's finances.

25% reported that they would like to be able to afford other treatments such as physiotherapy, occupational therapy, speech therapy and psychology.

"Our son's health comes first. However our finances have been affected substantially."

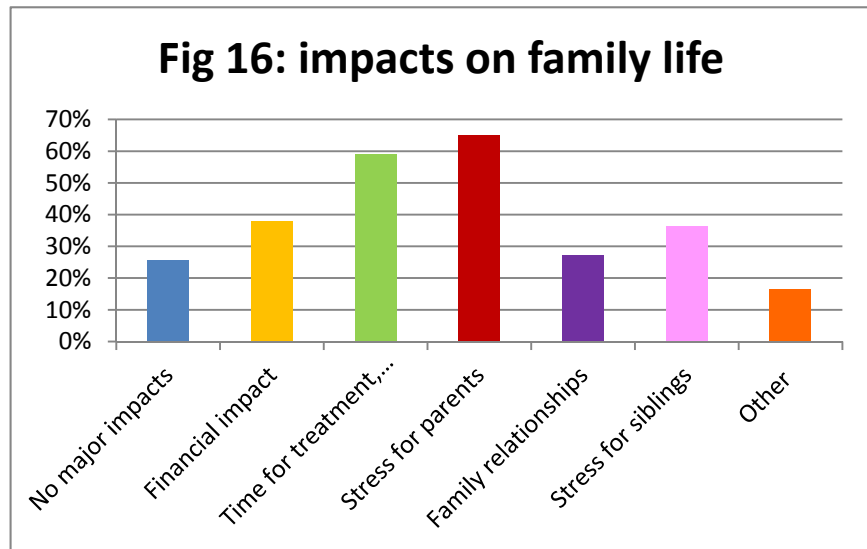
More than half the respondents stated that they qualified for carer allowance because of their child's juvenile arthritis, although people reported that this may have been possible after diagnosis but not once the condition was stabilised.



## Other impacts

More than 65% of families reported that their child's juvenile arthritis had caused significant stress for the parents.

59% of families reported that the condition had resulted in significant time devoted to treatment, travel of time off school or day care.



Significant financial impacts were reported by 38% of families, while 36% reported significant stress for siblings. 26% of families said their child's juvenile arthritis had had no major impacts on their family's life.

"Emotionally stressful to all involved, particularly in the first six months"

"It can easily break up marriages"

"We are getting there thanks"

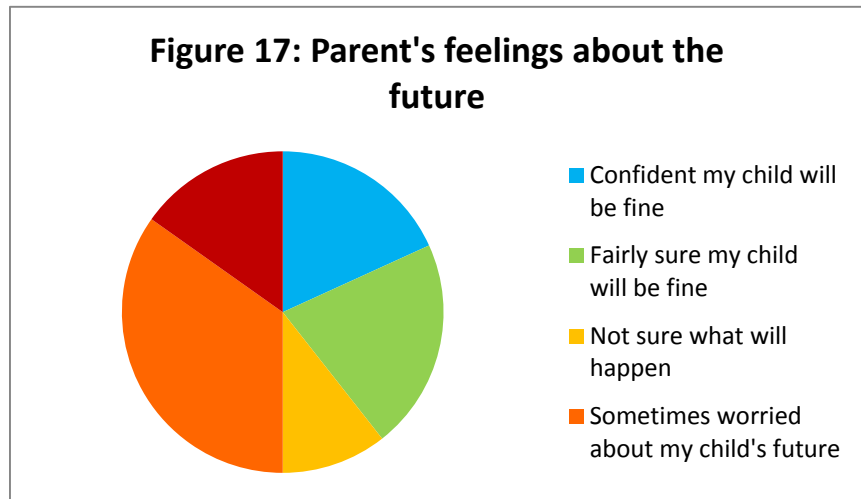
"We have a 6 year old as well that is an active outside boy and trying to balance both so neither boy feels left out is hard."

## Thinking about the future

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When asked how they feel when they think about their child's future, 35% of parents said they "sometimes worried" and 15% were very worried.

18% were confident their child would be fine, while 21% were fairly sure this would be the case.



One concern mentioned by several parents in their comments was a concern that treatment would affect their child's fertility.

## Action planning to improve the system

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Parents were asked to recommend improvements to the current services and systems available for children with juvenile arthritis and their families. Appendix 2 has the full listing, summarised below.

The most frequent suggestion was to improve awareness of juvenile arthritis in the broader community. More specific education of doctors, physios, educators was also a priority for parents.

The next most frequent response related to increasing access to services for people outside south east Queensland. Increased financial assistance to help parents cope with the costs of treatment and travel was also a popular suggestion.

The next most common responses related to activities to link children with other children with juvenile arthritis so they didn't feel alone, and to link parents as well.

Education/ awareness	16
Services outside Brisbane	10
Financial assistance	11
Kids' support groups and camps	8
Accessible, affordable hydrotherapy	7
Linking with others	5
More funding for Montrose Access	5
Subsidised physio	5
Doctors education	5
Information for parents	5
Support with impacts on schooling	5
Another paediatric rheumatologist in Qld	4
Better understanding by education providers	3
Counselling/ social work	3
Lower standards to qualify for PBS subsidy	2
Public paediatric rheumatologist	2
Earlier diagnosis	2
Appointments all in one day	2
Info on government assistance	2
More government support	2
Specialist support for acute flare ups	2
Emotional support for children and parents	2
More funding for research	2
More effective medication	2
More access to rheumatologist	2
Family get togethers / camps	2

## Some suggestions from parents

In their final opportunity to make comments in the survey parents raised the following suggestions.

"Ask the teenagers for their ideas"

"Continue exploring to find a cure"

"School holiday meet and greets in our area as we don't get to meet other kids"

"I'd like to see Montrose Access receive more government funding because they do such a great job!"

"Just the need for community knowledge on the severity of JIA."

"Private health some sort of claimable rebate for JIA."

"I think kids who have steroid injections and when newly diagnosed should be sent a care package to help them through."

# Appendix 1

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Responses to Question 23: what treatments or services have benefitted your child the most?

Treatment/ service	Number of respondents	Notes
Medication	14	Some respondents named the medications involved including Humira (2), Embrel (4), Methotrexate (12)
Medication + exercise/ physio	7	
Medication + massages	2	
Medication + joint injections	4	
Medication + joint injections + exercise	1	
Medication + joint injection + folic acid	1	
Medication + joint injection+ joint drainage	1	
Medication + joint injection + physio + orthotics	1	
Medication + joint injection + Montrose Access	1	
Medication + joint drainage	1	
Medication + psychiatry	1	
Medication + Montrose Access	2	
Medication + physio + advice from rheumatologist	1	
Medication + surgery + physio	1	
Joint injections	5	
Joint injections + physio + OT + ophthalmologist	1	
Joint injection + physiotherapy	2	
Joint injection + hydrotherapy	1	
Rheumatologist	1	
Rheumatologist + Montrose Access	1	

Montrose Access	3	
Physiotherapy	2	
Hydrotherapy	1	
Regular GP check-ups	1	
Natural medicine	1	
Natural therapies and physio		

## Appendix 2

What three things would most improve your child's or your family's ability to live with juvenile arthritis?

	1	2	3	total
education/ awareness	8	5	3	16
services outside Brisbane	6	3	1	10
financial assistance	4	6	1	11
kids' support groups and camps	3	2	3	8
accessible, affordable hydrotherapy	3	3	1	7
linking with others	2	2	1	5
more funding for Montrose Access		3	3	5
subsidised physio	2	1	2	5
doctors education	1	2	2	5
information for parents	1	4		5
support with impacts on schooling	4	1		5
another paediatric rheumatologist in Qld	1	3		4
better understanding by education providers	1	2		3
counselling/ social work	1	1	1	3
lower standards to qualify for PBS subsidy	2			2
public paediatric rheumatologist	2			2
earlier diagnosis	1	1		2
appointments all in one day	1	1		2
info on government assistance	1		1	2
more government support	1		1	2
specialist support for acute flare ups	2			2
emotional support for children and parents	1		1	2
more funding for research	1		1	2
more effective medication	1	1		2
more access to rheumatologist		2		2
family get togethers / camps		2		2
a cure - even just for the pain	1			1
support for medication costs	1			1
staying positive	1			1
more paediatric physios	1			1
help children regardless of nationality	1			1
doctors working together on treatments	1			1
more natural pain relief options		1		1
support for transition		1		1
better access to disability sticker		1		1
in home support		1		1
therapy groups		1		1
communication from specialists to schools		1		1
more information about cause			1	1



	<b>1</b>	<b>2</b>	<b>3</b>	<b>total</b>
education of school nurses			1	1
assistance with home modification			1	1
acceptance of natural medication			1	1
equal access to services no matter what state you live in			1	1
info about health professionals that can help			1	1
child friendly information			1	1
OT visiting state schools			1	1
discount for gym / sport memberships			1	1
pain management clinic			1	1
Subsidy for swimming		1		1
Easier access to home meds		1		1