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Stourbridge, Dudley & District
Voluntary Support Group

Your Group, working for you

Patient Satisfaction Survey

2010

Paediatric Survey

For children/ young people with diabetes and their parents /carers;

Why is this survey important?

Because it will show if the newly restructured diabetes service is working for YOU.

- This survey was commissioned by the DDIP (Dudley Diabetes Improvement Partnership), with production and postage funded by the Stourbridge, Dudley & District Voluntary Support Group of Diabetes UK.
- The survey was anonymous, with information provided for use in this audit only.
- The resulting reports and presentations were prepared by Mr Simon Hanson, a Committee Member of the Voluntary Support Group, in his own time.
- Notes under the 'Comments' sections are Mr Hanson's interpretation and/or summary of the actual comments provided by the respondents.

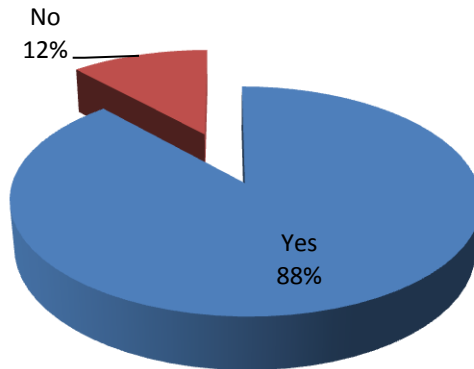
Paediatric Survey Report

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Section 1 – Your Child’s Diabetes Care

Question 1A - Do they attend the Paediatric Diabetes Clinic at Russell’s Hall Hospital

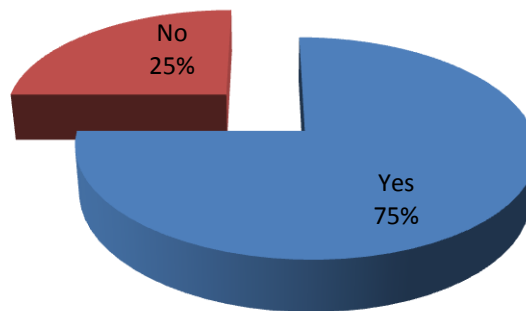


Yes	53	88%
No	7	12%

Comments

- Not now because she is 18, but we did for 13 years

Question 1B - If 'No' to question 1a, do they attend elsewhere?



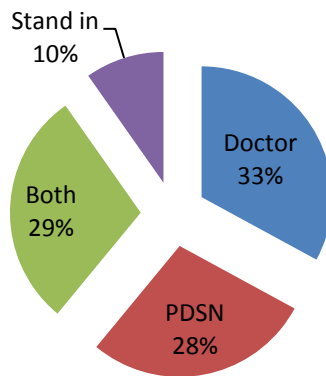
Yes	6	75%
No	2	25%

Question 1C - Please see appendix 1C

Comments

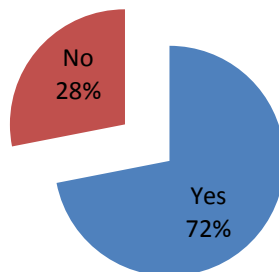
- Adolescent clinic attended as well
- Russell's Hall hospital children's out patients
- Been transferred in the last 12 months to adult clinic at Russell's Hall
- New Cross Wolverhampton
- Being transferred to adult unit at R.H. Hospital
- Also attend pump clinic in Brierley Hill
- We attend paediatric/ teenage clinic
- Heather centre Brierley Hill

Question 1D - Do they regularly see:



Doctor	27	33%
PDSN	23	28%
Both	24	29%
Stand in	8	10%

Question 1E - Are the results of tests carried out for their appointment discussed with both of you?

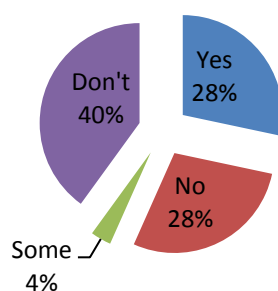


Yes	8.2	72%
No	3.2	28%

Comments

- My Child is 15 and is seen alone
- Usually have to ask for them, we asked for the last annual blood test so they could be carried out so form sent in post to us
- Only had 1 appointment as had diabetes 7 months

Question 1F - Are they recorded in the child's patient handheld record book?

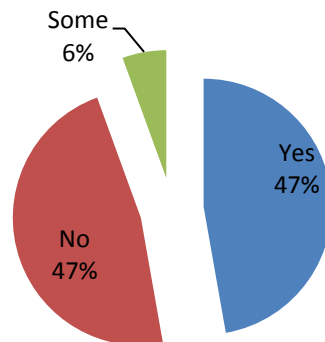


Yes	17	28%
No	17	28%
Some	2	4%
Don't have a book	24	40%

Comments

- We have a BM diary monitoring diary – the results are NOT written in this.
- Sometimes.

Question 1G - Do you both agree with the healthcare professional a target for your child to work towards before their next appointment, to better manage their diabetes?



Yes	17	47%
No	17	47%
Some	2	6%

Comments

- Not Always

Question 1H - Please see appendix 1H

Comments

- The DSNs do a very good job and are always there to answer question on the phone
- There is concern about delayed and cancelled appointments
- HbA1c testing via the post is very good

Question 1I - Please see appendix 1I

Comments

- There is concern over appointments being cancelled.
- There are long delays to get another appointment if its cancelled
- Alison is doing a very good job
- There is a need for appointments outside school/college hours

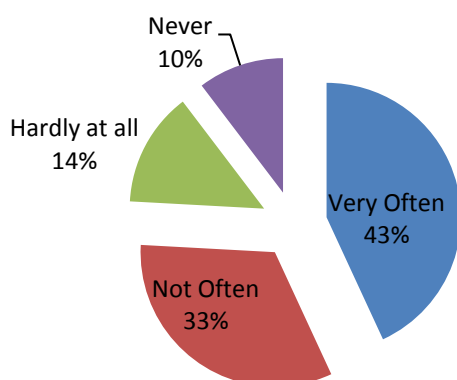
Question 1J - Please see appendix 1J

Comments

- HbA1c tests being posted in to the hospital, there were a lot of positive comments on the one.
- Use of insulin pumps
- Children are taken a lot more care of their own diabetes.
- A lot of respondent made no comments

Section 2 – Access to the service

Question 2A - How often have your child's diabetes appointments been changed in the last year?



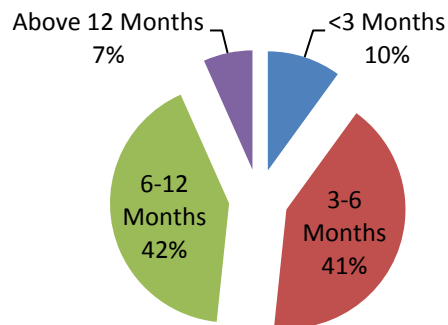
Very Often	25	43%
Not Often	19	33%
Hardly at all	8	14%
Never	6	10%

Question 2B - Please see appendix 2B

Comments

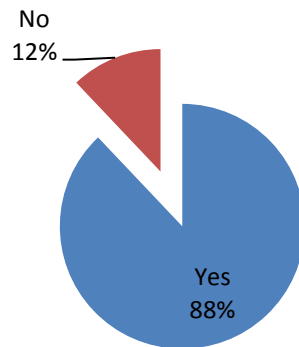
- No reason given
- Doctor off sick
- Doctor on holiday
- Respondents would like to know why there appointments are cancelled

Question 2C - What is the longest time between their appointments?



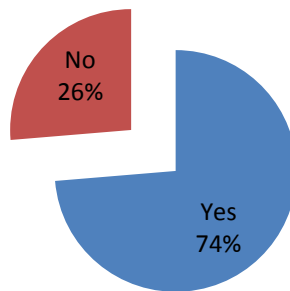
<3 Months	6	10%
3-6 Months	25	41%
6-12 Months	25	42%
Above 12 Months	4	7%

Question 2D - Do you (parent or guardian) have an out of hours contact number for diabetes support?



Yes	51	88%
No	7	12%

Question 2E - Are you happy with the level of your child's diabetes service?



Yes	42	74%
No	15	26%

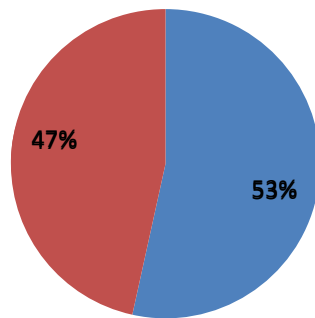
Question 2F - Please see appendix 2F

Comments

- Respondents would like a 24/7 phone number they can call with problems
- Respondents were concerned about the amount of appointment being cancelled
- There was concern over "Poor Service"
- Courses run by the nurses should be available evening & weekends for those who work.
- There is a strong feeling that that out of hours appointment are needed. Parents are concerned that their children have to miss school and college, particularly at exam times.
- They would like more DSN's.

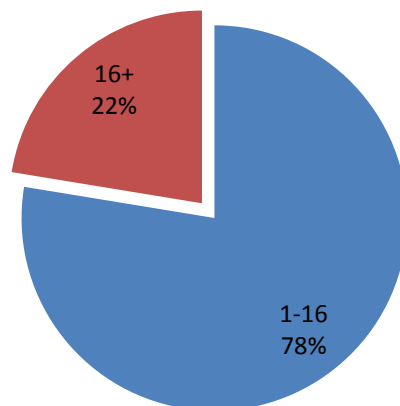
Section 3 – About your child/young person

Question 3A - Are they:



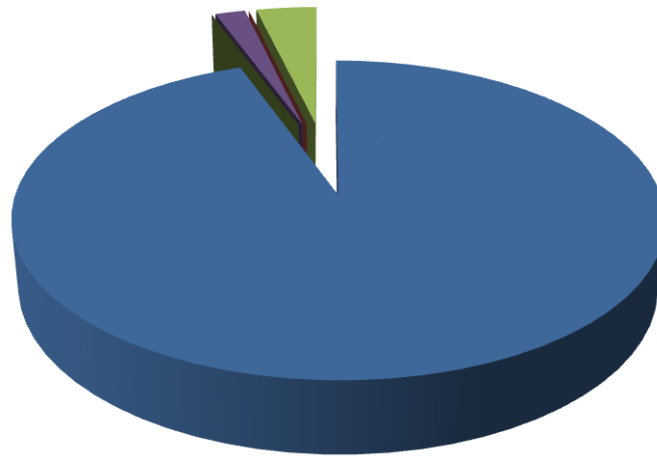
Male	31	53%
Female	27	47%

Question 3B - Their age please:



1-16	45	78%
16+	13	22%

Question 3C - Their ethnicity please:



- White
- Bangladeshi
- Indian
- Pakistani
- Black Caribbean
- Black African
- Chinese
- Irish
- Mixed
- Other
- Dont Know
- Prefer not to say

White	51
Bangladeshi	0
Indian	0
Pakistani	1
Black Caribbean	0
Black African	0
Chinese	0
Irish	0
Mixed	2
Other	0
Don't Know	0
Prefer not to say	0

Question 3D - Please see appendix 3D

Appendices

Appendix 1C - If not RHH Paediatric, where?

- Adolescent Clinic attended as well
- Russell's Hall Hospital Children's Out Patients
- Been transferred in the last 12 months to adult clinic at Russell's Hall
- New Cross Wolverhampton
- Being transferred to adult unit at R.H. Hospital
- Also attend pump clinic in Brierley Hill
- We attend paediatric/ Teenage Clinic
- Heather centre Brierley Hill

Appendix 1E - Are the results of tests carried out for their appointment discussed with both of you

- My child is 15 and is seen alone
- Usually have to ask for them, we asked for the last annual blood test so they could be carried out so form sent in post to us
- Only had 1 appointment as had diabetes 7 months

Appendix 1F - Are they recorded in the child's patients handheld record book

- We have a BM diary monitoring diary – the results are NOT written in this
- Sometimes

Appendix 1G - Do you both agree with the healthcare professional a target for your child to work towards before their next appointment, to better manage their diabetes

- Not Always

Appendix 1H - What works well in the present service

- Being able to contact the diabetes team nurses if needed
- The appointments at clinic work well usually. Last 3 month check up was postponed for 9 months two with no checkups
- HbA1c test results – new through the post
- The doctors keep a close eye on <name>

- Care on first diagnosis is excellent. The diabetic nurses are fantastic, so caring & supportive; they arrange everything even getting my son back to school
- Nurse Support
- At the moment everything is working well
- Appointments never cancelled, usually give enough time to discuss everything
- Nothing – A poor service to my child
- I find the child diabetic nurses very helpful. But worried now my child is being referred to the adult unit that there won't be so much support
- Diabetes nurses always on hand to help
- I am more than pleased with the present service
- Diabetic nurses are always there for guidance and support
- Paediatric nurses have a good relationship with my child
- All works well, gives up last appointment if poss it saves missing school
- Always get to see doctor or nurse – never had an appointment cancelled until recently
- I think the care is very good with Children's Dept Diabetic clinic
- The Diabetic Nurses
- Not everything works well
- Generally the nurses respond to telephone queries fairly quickly
- Hospital appointments enable you to get to know of the HbA1c results otherwise would not know. Can discuss insulin regimes
- ? HbA1c – home test
- Having doctor and DSN together at appointments; DSN always helpful when I call
- Staff friendly
- Checks seen though
- Very reassuring
- The HbA1c postal service
- The present service is adequate
- It seems to be a lot better seeing the specialist doctor and diabetes nurse together
- Paediatric nurse support invaluable
- Quality of care by all staff
- One to one help if required
- Don't really know just gets on with it
- Contact with the diabetes nurses at Netherton
- Diabetes specialist nurses – you can call for advice etc
- "When asking questions" they try to explain answers in a good manner
- Diabetic nurse team
- The new way of being able to do their blood test and send it in by post, very helpful
- The sending away of the blood to test the HbA1c
- Close contact with diabetes nurses
- Being able to see both diabetes nurse and doctor
- Good response from nurses
- Good in-house programme – Weight- Height- Advice- Dietary help
- Regular check ups
- All works well
- None
- HbA1c tests by post - fantastic improvement.
- Clinic @ new B. Hill health centre with DB Nurse + Pump specialist
- The New system of blood testing at home as not everyone has got use of a car to go backwards and forwards to the hospital

Appendix 11 - What do you think could be improved?

- More free appointments at clinic. My child's last 2 appointments at the hospital have been cancelled either due to staff shortages or holiday taken by doctor. As a result he has not seen anyone at clinic for 8 months which I think is highly unacceptable
- All appointments should not be in school/college time. There should be a choice of evening times as well
- More one to ones with children with no parents in the room to make them express themselves freely on how they feel
- Regular appointments, glucose sensor, more diabetic nurses, drop-in clinics
- Latest appointment @ hospital is 4pm – have to take son out of school - he is now doing GCSEs so don't really want him to miss lessons; a 4:30 appointment or Saturday appointment would be better
- Happy with service
- Nothing
- Feel we have lost continuity since transfer to adult clinic
- A better understanding by the health care team of the difficulties of living everyday with the condition
- Everything – like I say above – poor service to my child
- Nothing really, at nearly every appointment my child has seen the main consultant
- Maybe out of hours support for non-pump users
- Nothing, I am very happy with service provided
- More diabetic doctors
- Specialist, full time consultant
- Dietician provision
- Better access to appointments
- Appointment out of school hours
- Would like to see diabetes doctor every time instead of stand in
- More adolescent clinics, our daughter's appointment has been postponed for 5 months!!
- Appointments not keep being rearranged
- The appointment system
- That there is a back up doctor to take clinic if your doctor is unable to; that would stop appointments being cancelled
 - 1 appointment at clinic need to be more person centred and regular
 - 2 waiting time in clinic is too long
 - 3 There currently needs to be backfill for doctors and nursing posts
- Because of above, appointments should be more regular for teenagers and annual blood tests carried out should be annual and not longer in length
- Timescale – quite often my appointment time is late – never actually given a time
- Appointment times – cancelled kept waiting
- Better relationship/Understanding between doctor and patient
- Waiting Times
- Seeing the child more often
- Less cancellations of appointments. I think an evening clinic would benefit the children. The children shouldn't miss out on education just because they have diabetes
- More nutritional advice. Closer monitoring
- More funding to that people have a choice of they would like a pump etc
- Appointments – not being cancelled every time sometimes 2-3 times
- Waiting times in clinic - causing unnecessary time away from university

- Regular communication with follow up treatment
- Appointment had been cancelled at least 4 times
- Appointments always being cancelled and then re-booked and cancelled again
- More contact in the “management of diabetes” and try to keep appointments “and on time”
- Appointment times
- Regular appointments needed, training and knowledge transfer to parent needs
- Stop changing appointments when made
- Children (my son is 12) should be better educated to help further understand diabetes and its lifelong affect
- I feel if an appointment with a consultant is cancelled once it should not be cancelled again and you should get a call from your diabetic nurse to make sure everything is ok
- Diabetes specialist consultant.
- More diabetes nurse cover, Alison is doing a fantastic job ON HER OWN
- Interaction between the GP and hospital. Retinopathy eye-screening results do not seem to be passed on. The results of these tests are now really discussed

Appendix 1J - What recent improvements (in the last 6 months) have made a significant difference to your child’s care, if any

- My child having more confidence in treating his diabetes and seeing other children with the same medical condition at the race day organised by yourselves
- None because the hospital keep changing appointments
- My child taking more responsibility for diabetes but knowing the nurses are a phone call away
- None
- My daughter has not long been diagnosed and I am totally satisfied with her care
- Putting blood sample on card (HbA1c test) and posting in is far more convenient than going to hospital for blood tests.
- HbA1c blood tests every 3 months being done by post
- Now my child is at adult clinic have less knowledge of what is discussed during appointment but recognise he has to take full responsibility especially as going away to uni.
- Nothing
- No improvements, everything still the same
- My Son now uses a pump which has made a huge difference to my whole family
- The insulin pump which my child began in the last 6 months has meant we are now seeing diabetes nurses every 3 weeks
- Blood tests on blotting paper
- As Above
- Child is now on an insulin pump – much better to live with
- Not had an appointment in 13 months
- Not able to think of any
- Have worsened since he has got older, my child has not been seen by a doctor since November 2009
- Going from (2 * novo mix injections) to 3 injections including a 24 hour back ground insulin and carb counting. Using the nova rapid before an evening meal
- He’s had a pump fitted
- The HbA1c test – now done at home and posted to the hospital
- “More needles, as brought her blood count down. But would like it better”

- Changing to multi-injections rather morning and night
- Carb Counting
- Pump
- <Name> has been put on carb counting and is working very well
- Hba1c test cards
- Introduction of pumps. This has changed our Childs life & well being even if we aren't yet getting stable results we would like. It is well worth all it involves

Appendix 2B - What was the reason given for the cancellation of your appointment

- Staff shortages + Doctors holiday (notified the day before the appointment then another appointment arrives for another 4 months away. By the time of his next appointment it will have been 10 months since he has been seen, He has only been diagnosed since Nov 09
- Changed by the hospital
- None, just letter noting appointment change
- No Reason - (Just necessary to change)
- Doctor was not available for one visit
- No reason given, but when trying to change the amended appointment. I was told the consultant was off sick.
- Only consultant no registrars, not able to manage clinics, sickness
- Have not been told what reason
- Illness of dr.
- Consultant unavailable
- Doctor
- Consultant Holiday
- Only recently appointment cancelled because doctor off ill
- Unforeseen circumstances
- The Doctor not being available
- Cannot remember for the first cancelation, but for the second doctor on sick leave
- Firstly because of a shortage of doctors, then subsequently no reason given
- We cancelled because of GCSE exams at school and then the hospital cancelled appointment - no reason given
- The Specialist doctor was ill / Holiday
- No reason just letter + new appointment
- Not explained just letters saying appointment delayed
- Doctor unavailable (On Holiday all the time or Sick)
- Holiday
- Doctor on sick leave
- Can't Remember
- Doctors on holiday, ill
- No reason or doctor not available
- Lack of staff & Staff holidays
- Had to be re-arranged

- Twice <name> appointment has been changed in the past. This time i had to change his apt in May 2010 as he had a GCSE exam. But now his apt. has been changed again till Feb. <name> won't have seen a doctor for 9 months.
- Unknown
- "it has been necessary to change you appointment"
- Doctor ill
- Sickness, Holiday, NHS CUTS!
- Usually Holiday, but still always see DB nurse.

***Appendix 2F - (Are you happy with the level of your child's diabetes service?)
If not, why not? Please write your comments below:***

- Yes + No. I feel because we have a good control of his diabetes at home that there is no threat to his condition although my child feels the doctors don't care about him because of all the cancelled appointments. He has not had HbA1C since Jan 10. So we are a bit worried what his levels will be
- Appointment has been cancelled numerous times and changed this year. Also there needs to be an option of appointments not during school/college hour. Particularly for older children as exams/work take priority
- Appointment being cancelled does not help track AbA1c. Equipment is available to help reduce the effect of contact with health officials, but cost is prohibitive.
- Cannot understand why another doctor could not take the cancelled appointment. We have had four appointments previously and only once seen the consultant, so why couldn't we have seen another doctor
- We need a 24/7 telephone support line with a diabetes specialist on the end. This does not need to be locally based as long as those responding understand the different regimes people are on.
- It's a poor service and needs a lot of help to put to a good service.
- As parents we are informed on our son's blood results, no feedback whatsoever. It's a poor service and i think it's just getting worse year by year
- We have not seen a doctor since March + next appointment not till November this is not good enough
- Thank Goodness for the diabetic nurses
- If an appointment is changed it is moved by 3 months meaning sometimes appointments are 6-9 months apart
- Even if you/the doctor request an appointment after 3 months at clinic it is almost impossible to get one before 4 months
- 24/7 helpline with diabetes specialist at the end of the phone
- Better maternity cover- the one nurse at the moment is far too stretched
- A little concerned that only 1 diabetes nurse working at the moment. But always returns calls swiftly and sort's out concerns
- More support would be nice, if an appointment is changed once, shouldn't change it again
 - As parents we feel that we are left to manage our son's diabetes and have to constantly chase health professionals for support. Bombarded with info to begin with then nothing.
 - The courses run by the nurses need to be run at weekends or in the evening due to our work commitments we cannot attend Mon-Fri in the day.
 - There appears to be poor inter-disciplinary working between doctors e.g if a child has more than one condition and seeing another doctor as well as the diabetes

specialists, they do not seem to communicate effectively and will only concentrate on their speciality – although one condition may affect the other

- Appointment cancelled by hospital for 21/09/10. Next appointment 18/01/11.
- Too long to wait to be seen. At least 3-4 monthly HbA1c should always be carried out regardless of whether there is a hospital appointment or not. A system could easily be put in place for these to take place and results given to the parent/career either by post, email, GP surgery, clinic.
- Inconsistent
- The amounts of times the Dr cancels the appointments are appalling. When we do eventually go to the clinic I specifically make my next appointment to ensure it is after school as my daughter's school takes a dim view on time off for appointments. When we get cancelled appointments - letters, typically - the new time will be within school hours. The new appointment is for 3 months after the original appointment which I do not find acceptable.
- Clinics are run during school hours – not good in teenage/GCSE/A Level years. Appointments booked on holiday are always cancelled at short notice – meaning that we have to wait months for the next available shot
- Diabetic nurse team fantastic, but they bear the brunt of cancelled appointments. It is easy for DRs to talk jargon and forget that this is all new to some parents and children. Too many people in consultations upsets child.
- The only thing I am not happy with at present is the constant cancelling of appointments – my son is supposed to see his doctor every 3 months and it will be nine by the time his next appointment comes around (that is if it has not been cancelled again)
- Not happy that <name> appointments have been put back 4 times, to which in-between he was admitted to hospital and still has this appointment put back.
- The last time <name> saw a doctor was March and hasn't got to see a doctor until November - (THAT'S IF ITS NOT CHANGED AGAIN)
- Usually yes but I'm disgusted this time as he has got 9 months to be seen by a Dr as no available appointment left!
- When contacting out of hours it would be nice to speak to someone who knows a little about the condition and not to be fobbed off and told to ring the nurse on Tuesday when it was a Saturday on a bank holiday weekend!
- Like everything – you always want more and something's could be improved like more DB nurse support etc. Recognise though it is all about balance
- I missed one hospital appointment for my child and was left without any care for over a year despite phone calls to the diabetes team. In the end I was told I would have to re-register with my GP. Then wait for an appointment. This meant over a year with no check-ups at all whether any damage has been done I don't know.

Appendix 3D - Have you or your child any other comments? Please note them below

- My Child would love to be in a group with other diabetic children to talk about worries he has and what they think
- If we are to support our child with diabetes with little support, then we would feel better if we were afforded the technology to best facilitate our needs, and aid earlier correction of sugar level trends etc
- <name> team do a fantastic job with her and I'm very grateful to them all

- My daughter has not been seen in clinic since Jan 10, not scheduled appt Nov 10, But this may be put back again. I have ensured she has had her HbA1c done every 3 months and we have seen the nurse at home and spoken on the phone
- This page is not big enough for how i feel my son is treated POOR!!!
- The support we get from the PDSN's is great and we feel very looked after. I have no issues at present with our care
- None
- Treated very well at the clinic at RH by Dr Mohite.
- Can't complain about service provided other than would prefer to see doctor instead of a "Stand-in"
- Evening clinics should be available so they don't have to miss school
- I am very pleased as a parent with the care and dedication of the diabetes team. We never missed an appointment and we continue now at the adult clinic at Russell's Hall hospital
- Thank You
- Appointments at clinic are rushed and feel impersonal.
- Other venues, other than Russell's Hall, to be considered
- For clinics, parking is abysmal
- Introduction of a new diabetes nurse at home was appreciated and couple of telephone calls to ask how my child is getting on but this is in nine years of living with diabetes pretty poor ready
- Check up phone call - monthly
- We don't even know that the diabetes service had been newly restructured
- I think it would be a lot more beneficial if more information was available regarding better control i.e. pump. Is funding available etc?
- Our appointment has come through as January 2011, we haven't been to the hospital since January this year (hence doctor away or on holiday) this is why we attend the health clinic
- "Would like to attend a local clinic, which would be better, for going back to school and save time"
- Thank you to the staff @ RRH who on Boxing Day 2009 cared for our son who was newly diagnosed type 1. Particular thanks to the diabetic nurses.
- An annual newsletter telling parents of potential new breakthroughs
- I find all of the team very friendly and I feel if I need them I can ring and speak to someone.
- Not happy the way we have been treated with reference to his appointments
- Young Adults Teens need further guidance off specialists. The attitude "can't be bothered" needs sorting through knowing or better seeing the consequences
- It would be nice to have a set person to deal with and to be told the same advice by everyone, and when promised to be called back for this to happen
- DB nurses are fantastic Alison deserves a medal for all support she is giving on her own. We are generally pleased & again the introduction of a pump has changed our Childs life for the better
- I think if you are not happy with the consultants you should be able to change but do not know what the procedure is if you do want to change