

EFCCA Youth Group Transition Survey 2017 Report



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Introduction

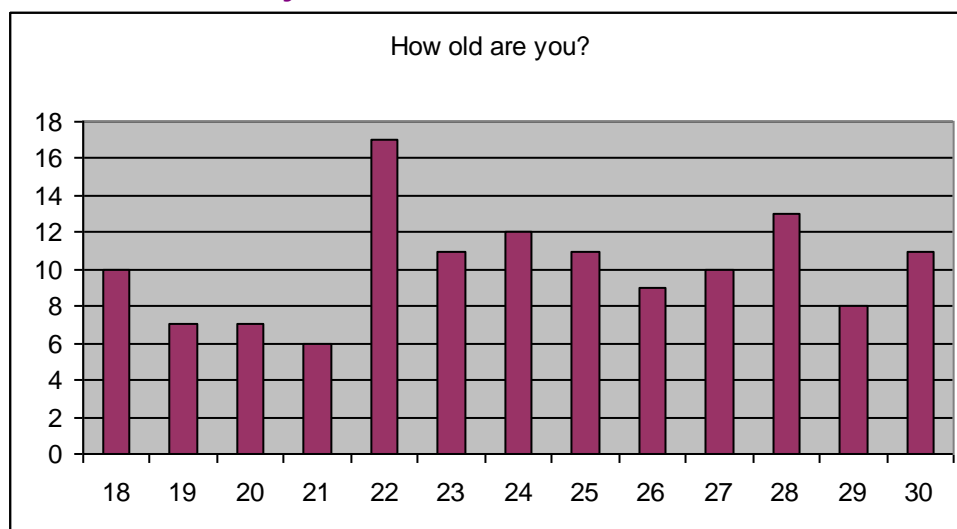
The EFCCA Youth Group wished to get young IBD patients experiences on the transition process. The Transition Process is either from Pediatric to Adult care or simply changing hospitals.

The Survey was for IBD patients aged between 18 - 30 with a view to getting a better understanding of the transition process and where improvements and changes were needed to make the entire process better for the patient.

The information contained in this report is intended for reference purposes and to generate ideas for...

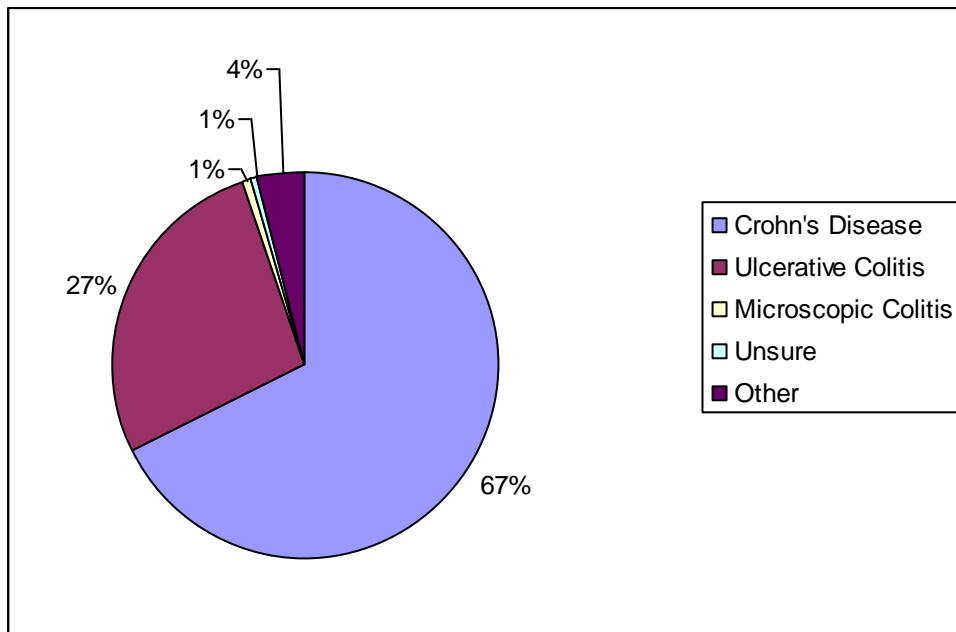
THE SURVEY

1. How old are you?

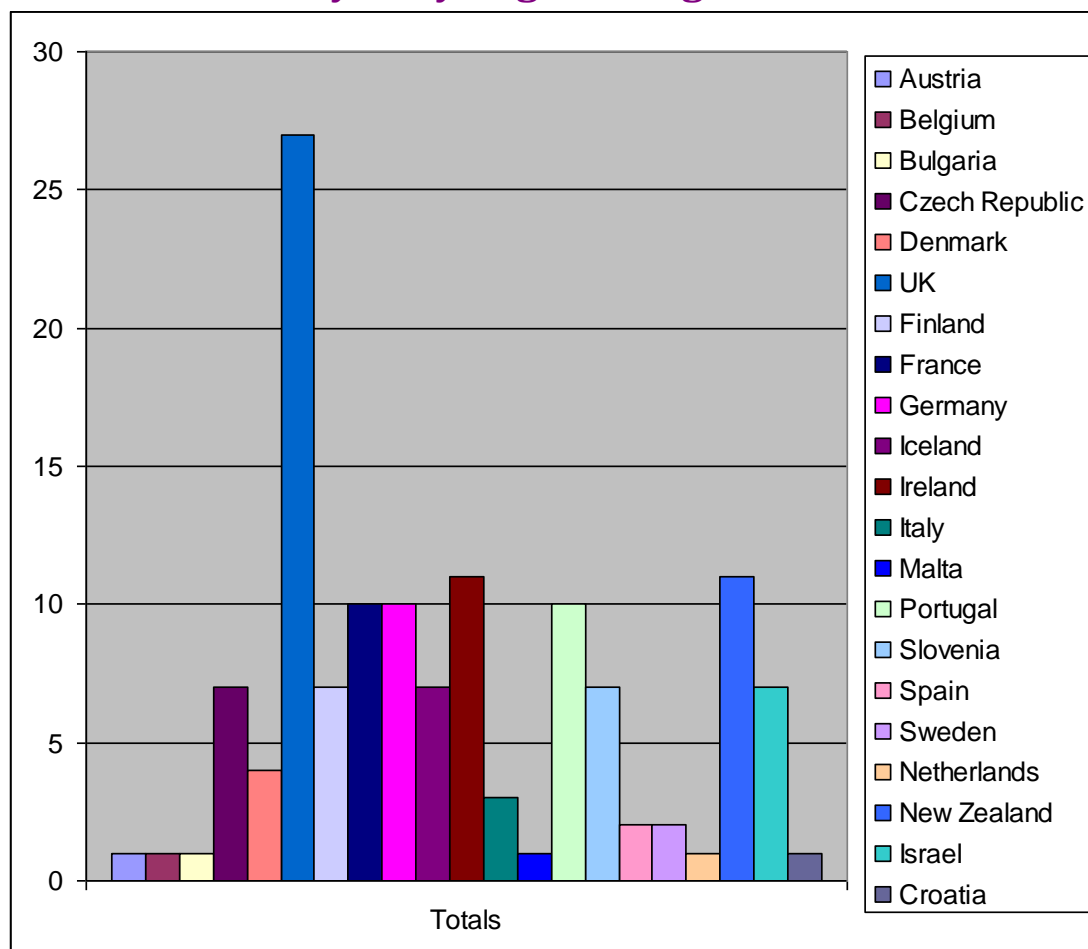


The responder's average age was 24 years old with the most common age being 22 years old

2. What are you diagnosed with?

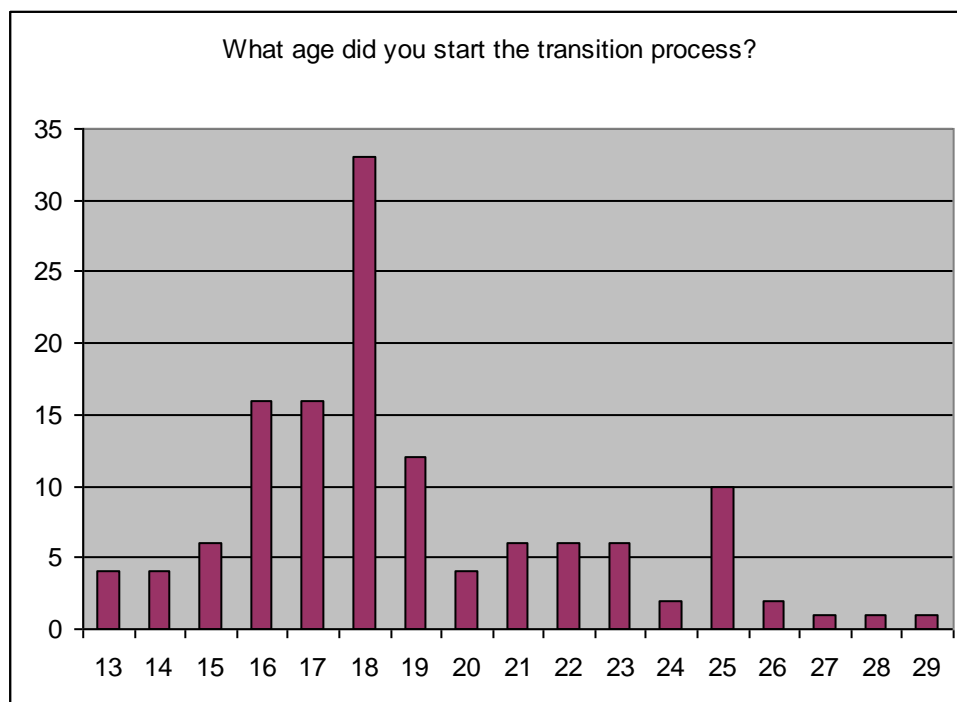


3. In what country did you go through transition in?



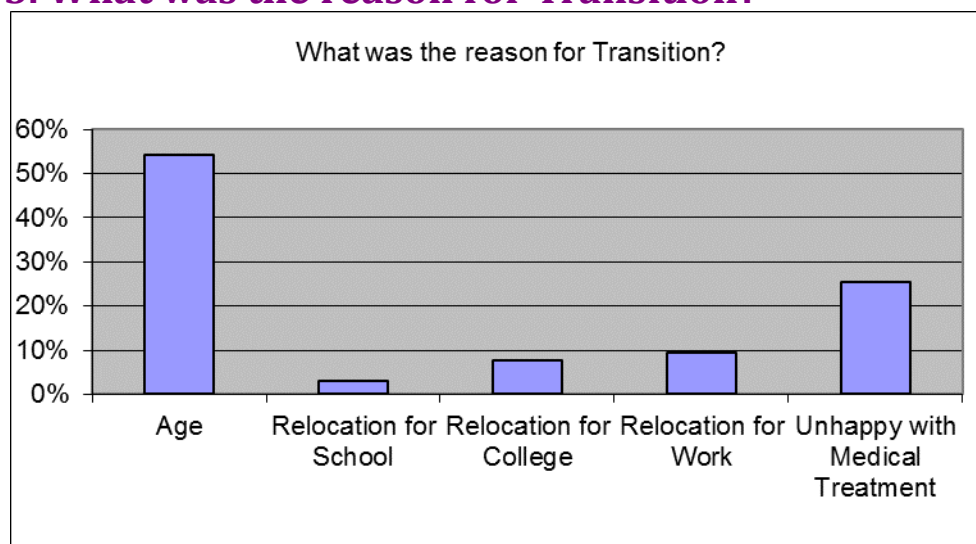
21 countries took part with the UK being the biggest contributor. On average each country got just over 4 responses.

4. What age did you start the transition process?



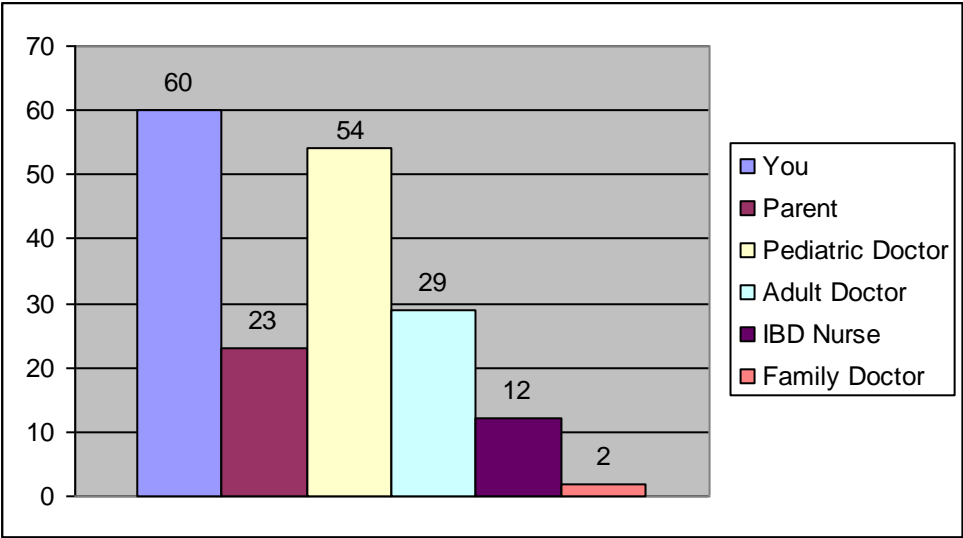
The average age for transition was 18.9 years old with the most common age being 18 years old. Surprised how many people transitioned after 20 years old (27%) but they could have moved due to school, college, relocation for work or unhappy with medical treatment.

5. What was the reason for Transition?



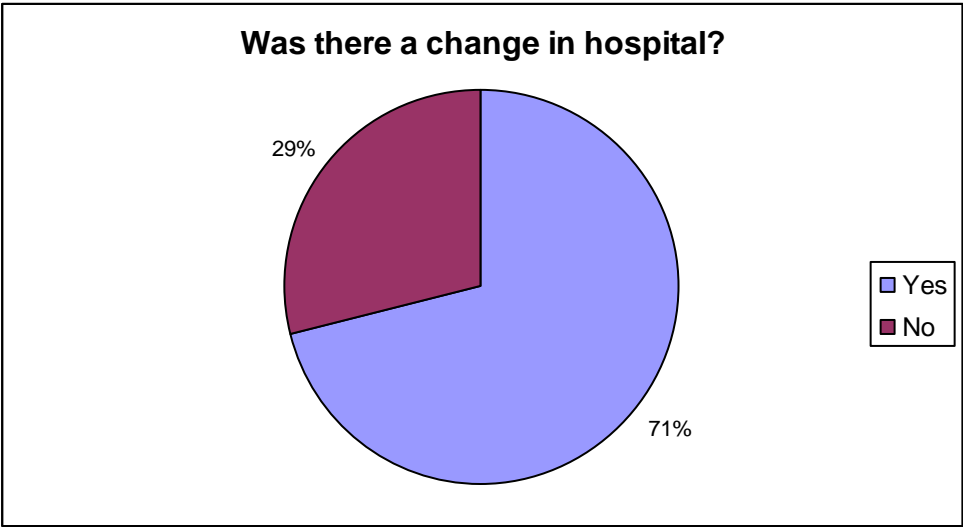
Age was the most common reason for transitioning with sadly 'Unhappy with medical treatment' being the reason for 26% of people

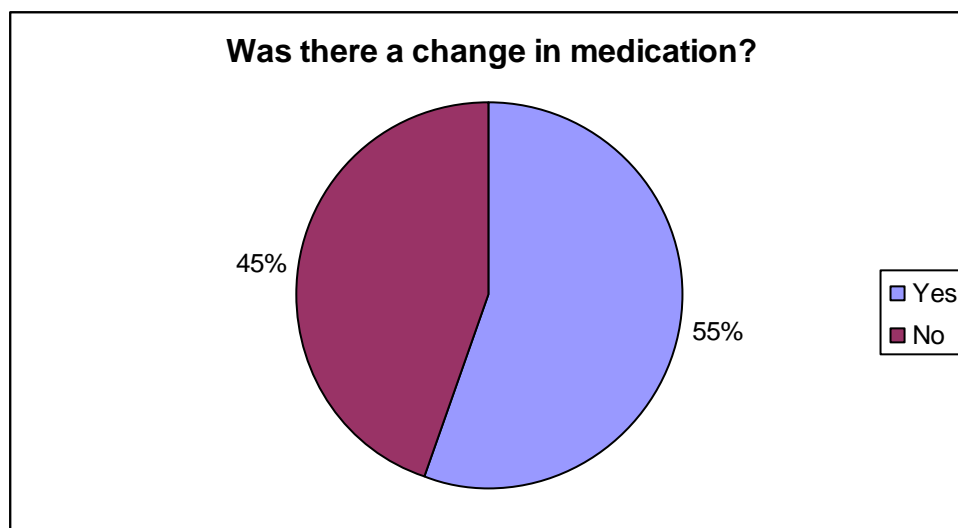
6. Who decided when you would transition??



This was multiple choice answer as most decisions are not always taken in isolation by one person. The patient had the most say in when they switched followed by the pediatric doctor however when combining the Patient and Parent they only had a say 46% of the time with medical professionals having a say 54%.

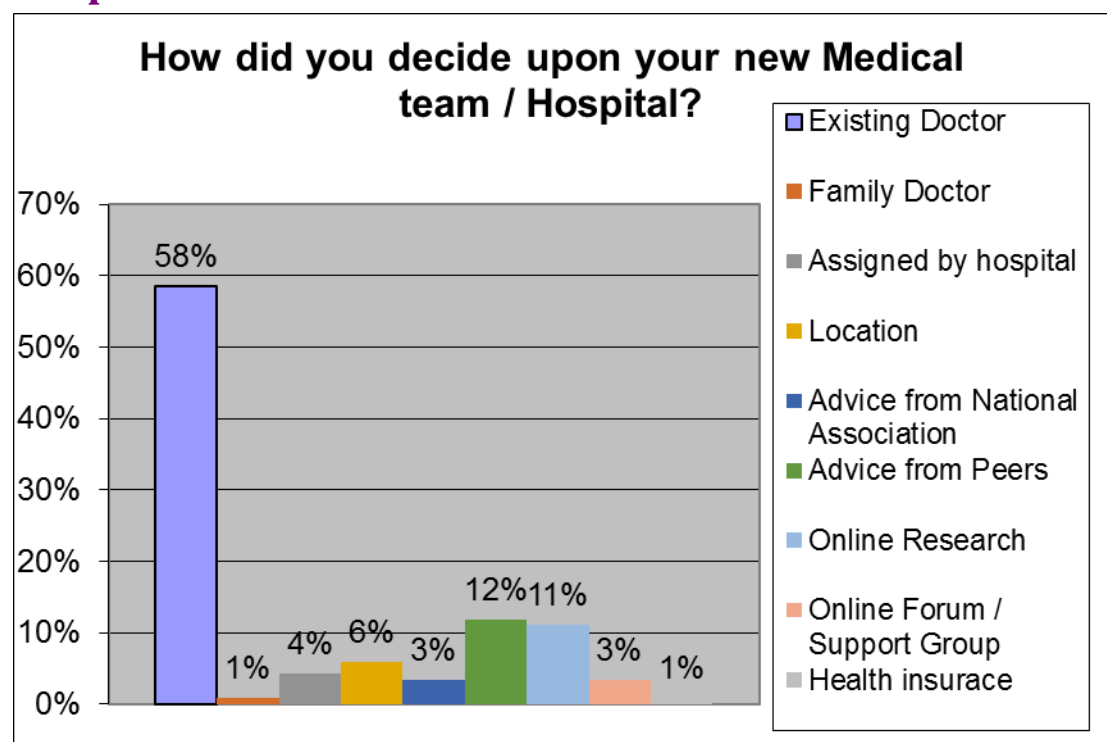
7. Was there a change in Hospital and Medication?





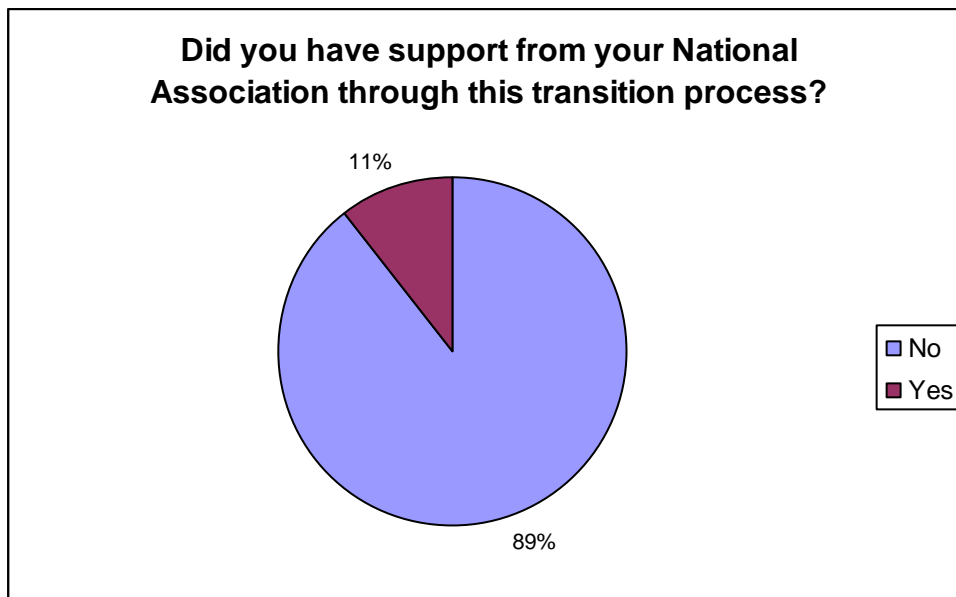
For 55% of patients they changed medication during transition which does seem worrying although without further details it's hard to make a real judgement especially when looking at patients change in health was evenly split in question 14.

8. How did you decide upon your new Medical team / Hospital?



Unsurprisingly the existing doctor plays a very key role here however 27% did seek advice from peers, online or in support groups which shows a desire for people to do their own research and how much other people's experiences are valued in this process.

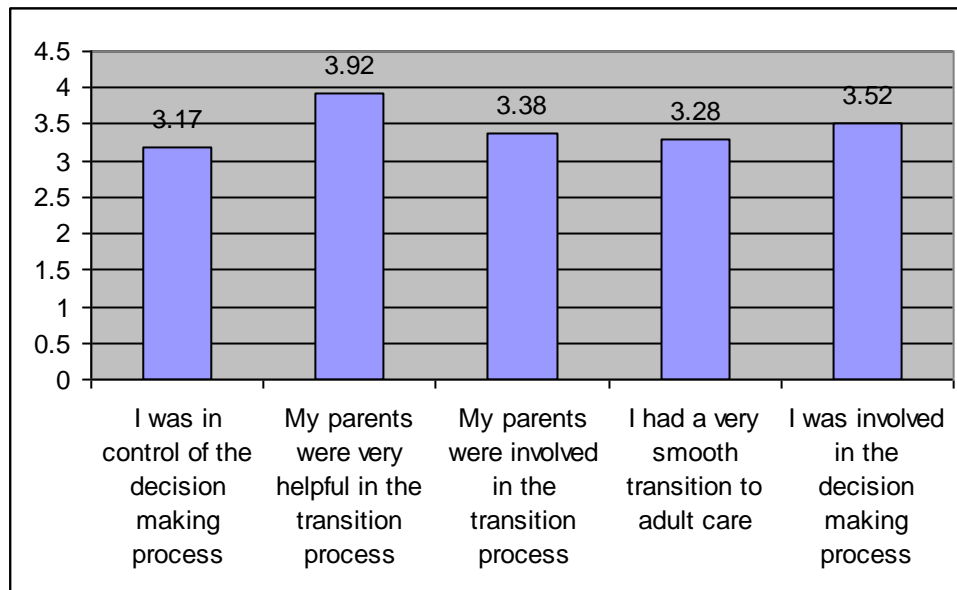
9. Did you have support from your National Association through this Transition process?



14 people said yes and the support they got was

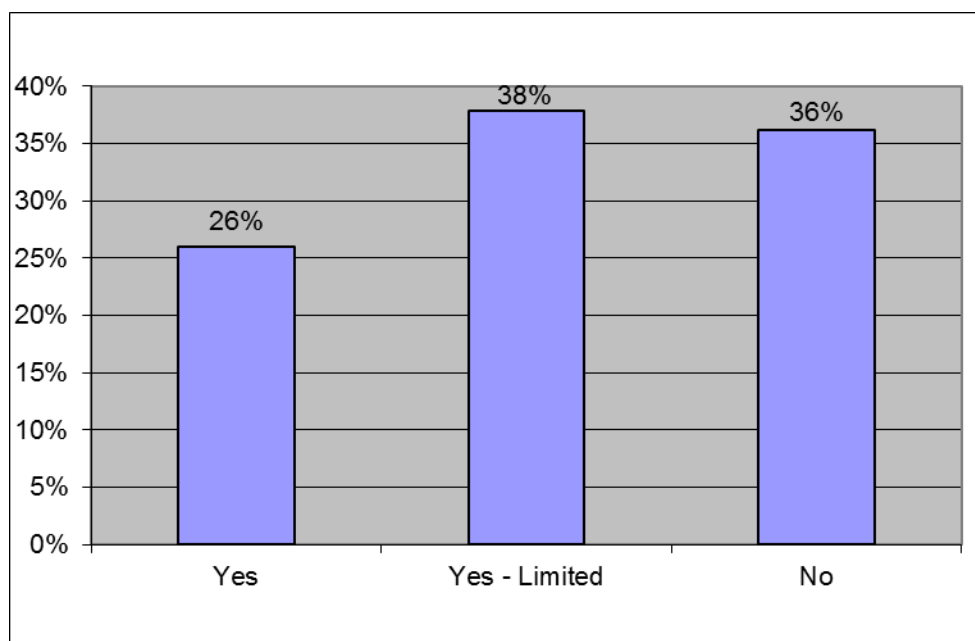
- Moral and documentary support.
- The association recommended a doctor told (medical treatment issue)
- Information from facebook group
- Young online association group
- List of other doctors (age transition)
- They made sure I got the same treatment I was getting with my former doctor. which was working. (age transition)
- Advise for a new doctor (work location change)
- I knew that they have a list with names of good doctors if needed (unhappy with treatment)

10. How strongly do you agree with the following statements?



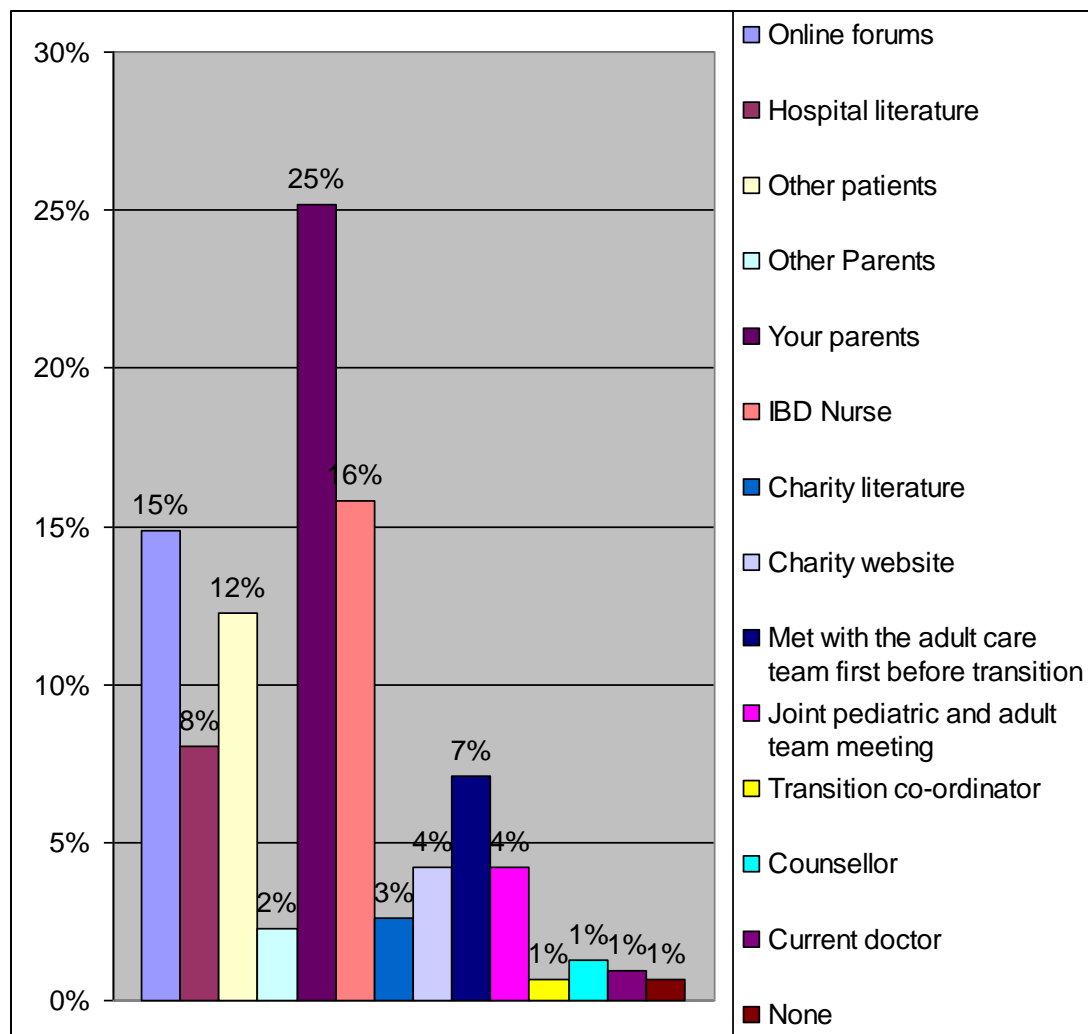
5 would mean strongly agree and 1 is strongly disagree.

11. Was there any communication between new and old medical teams?



Good to see that there is seen to be communication between new and old medical teams although 36% is way too high for patients who saw no communication especially as this was a main reason that people's expectations of transition were not met in question 13.

12. What support did you get? (select all that apply)

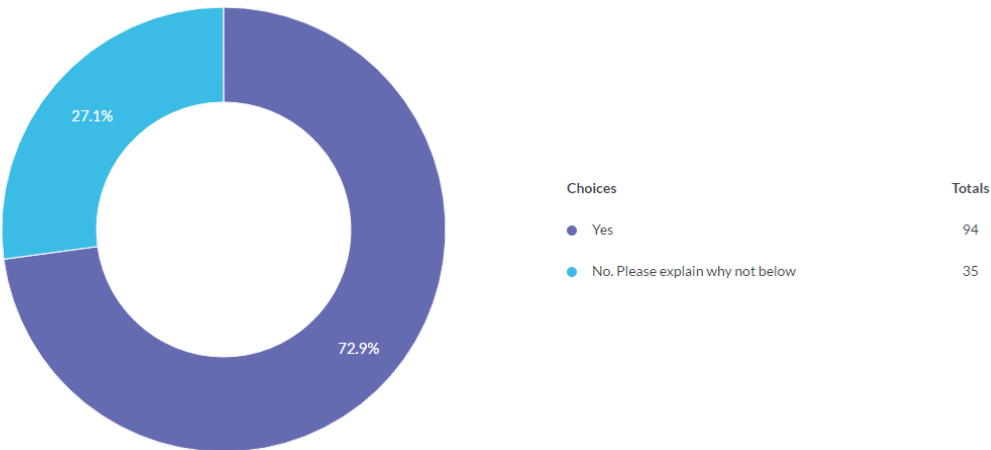


This was a multiple choice question with Parents being the most common source of support (25%) with IBD Nurse (16%), Online Forum (15%) and Other Patients (12%) the next most common.

Doctors (14%) seem to be relied upon less for support than IBD Nurses (16%) which shows the nurses importance especially as we know that not every patient has access to one.

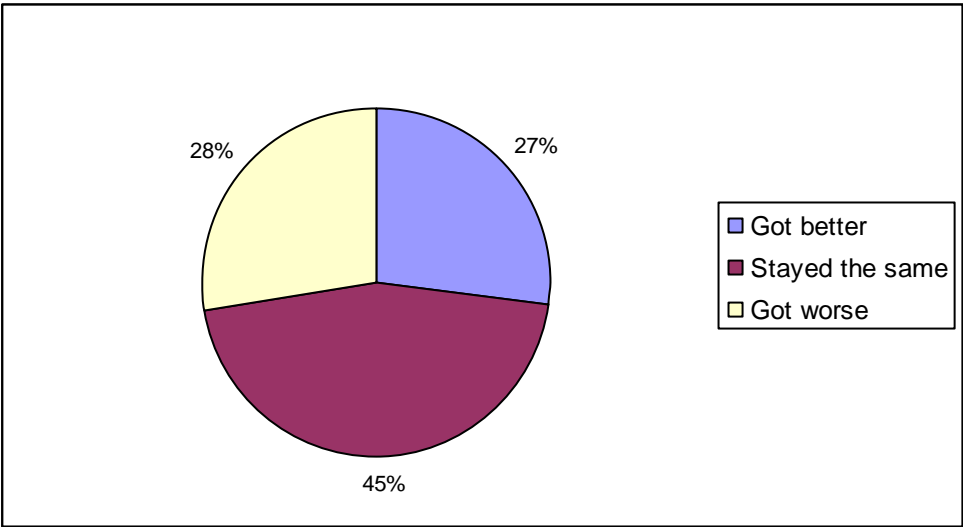
Online forums (15%) are used just as much as hospital/charity literature/websites (15%) which shows there is a need not being met by the quality or the type of information. This could be simply the power of other patients experience which was 4th overall response but if combining this with Online forums it would be top result (27%)

13. Did your transition meet your expectations?



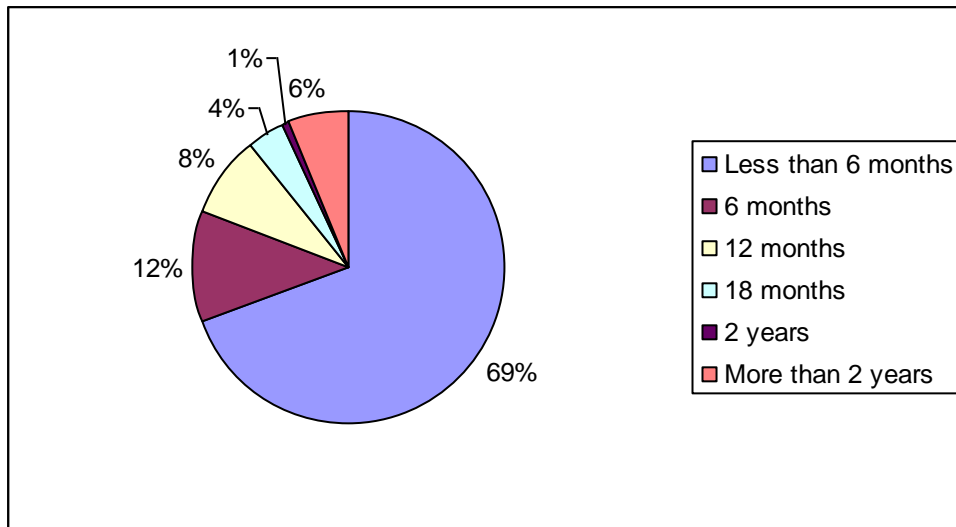
Great to see 3 out of 4 people had their expectations met however 25% didn't and this is still too much. Common problems was a lack of communication either with patient about the process, passing on records to new doctors or simply informing the patient who they should contact now about their care if they have issues. Even when there was a transition letter this would overall the wishes or the voice of the patient. Some also commented on the less attention received in adult care and the feeling it is more busy and chaotic. For detailed comments see Appendix 1

14. Did your condition change during the process?



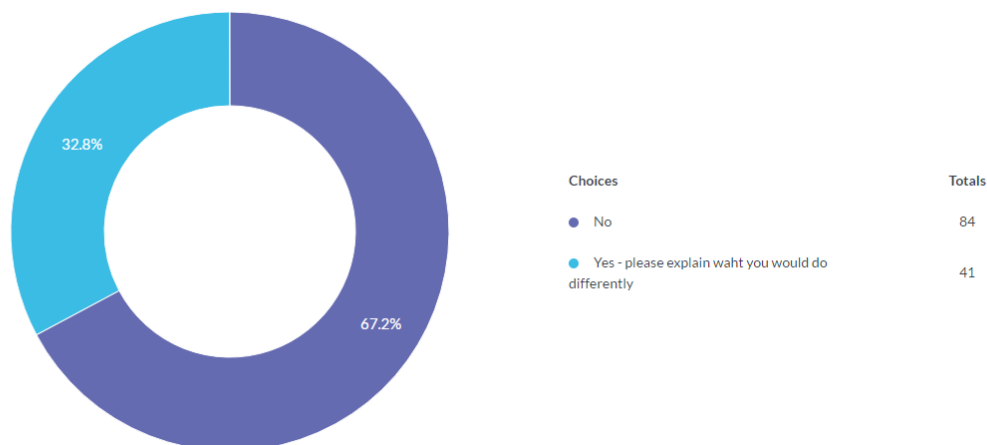
This is reassuring that 45% of patients health stayed the same and although 28% got worse during the transition period a similar amount of 27% got better.

15. How long did the transition process take?



89% of patients complete transition in 12 months or less with 81% being done after 6 months.

16. Would you do anything differently?



Good to see that around 2 out of 3 people were full contact with the process and would not change anything however 33% is quite a large amount of patients that would seek to do things differently next time. Of those who would do something differently 13 would choose a different hospital or doctor with others commenting on the smoothness of the transition around communication and knowing who to contact. Some mentioned (3) that there was no real transition period they just started going to adult care which they didn't like. For detailed comments see Appendix 2.

Key Points

1. Parents play a key role so support and education needs to take them into account too.

2. Patients use other patients for guidance the most so how can national associations support this through online forums or sharing experiences in information sheet, booklets and events
3. Lack of national association support so most are left to fend for themselves via friends or hospitals
4. IBD Nurse plays a key role in support, more than doctors.
5. Majority of people have their expectations met (73%) but still not same experience for everyone.
6. Communication with patients around the change and between the two hospitals or departments seems to be the main issue when problems occur

Survey Limitations

1. Not asking parents as they play a key role and may have more indepth knowledge if they took the lead or advocated for their child
2. Combining people who moved hospitals with those who moved from pediatric care has skewed some of the questions due to the inability to separate them out.
3. Not asking age diagnosed
4. Limitations of software used as hard to compare questions against each other
5. Although 21 countries were represented, on average each country only had just over 4 responses making any individual country analysis weak.

Appendix

#1

13. Did your transition meet your expectations? - No

- We are completely abandoned during the passage in grown-up service and all the relational side is lost. The violence in these services is permanent.
- I felt like thrown away. No one looked after me anymore and new doctors didn't want to listen to me or get to know my story with illness.
- Notes weren't exchanged between new and old hospitals. Had to explain history to new hospital several times
- Pediatric team promised that colonoscopy would be done under anesthesia but adult team refused and I didn't get any premedication.
- I decided to switch doctors but the new doctor is as bad as the old doctor. Not answering emails in weeks or months and I can't reach him via phone (that takes longer). I have even been out of meds because of it.
- It took too much time. (less than 6 months but had to change for school)
- Too hard, diving directly into the swing of "adults"
- New hospital took old hospital's opinions before any further examinations/investigations due to transition letter. Years later requested change of hospital to one of my choice via GP referral and now receiving excellent care and treatments

- I didn't see an IBD nurse or Consultant for a year!
- At my first appointment in the new hospital I waited for 4 hours to see the new consultant. Eventually I found the IBD nurse who explained to me there was some sort of mix up and the consultant had finished the clinic. She then arranged for the registrar to quickly see me but I felt quite let down and frustrated by the experience.
- My new doctor "undiagnosed me" when I moved to a new hospital then 3 months later when 1 page of my notes had eventually been transferred to the new hospital after at least 6 phone calls by me and the hospital he "red Diagnosed me"
- No communication or preparation before hand
- I felt I don't have enough care (less testing, short meeting with doctors)
- I had to try out 4 doctors before I finally found a proper one
- It was a very big chaos
- I had only one 'transitional' appointment before I was moved completely into adults
- Had a very bad first experience with adult team after being admitted in hospital with them making big decisions without them understanding the severity of my illness
- The process of changing hospitals from quite scary and I never felt like I was supported well by the medical teams to help me transition
- Time I met my new doctor was when I needed another infusion of Remicade. Before that no one knew who will even be my doctor. I went from pediatrics to adult hospital without even knowing where to go or turn to in case of not feeling well. As soon as I came to the new doctor he changed my Remicade dosage, even though I was strongly warned that they mustn't change the dosage because I just came in remission. Since then I have been out of remission, had 3 hospital visits and have constant battles with my GI. Doctor.
- I am still waiting to be properly treated, due to some issues with the insurance
- Been without a doctor for a year now
- Wasn't happy with new doctor
- The new team didn't seem to want to get to know me or to let me get know other services that might be available within the hospital. Before I changed hospitals I knew who the contact person was for each service I needed but when I changed hospital I was not giving any of that info i.e. contact details of IBD nurse
- At first few months yes (because new medical team gave me a new medication), but after one year, I wasn't satisfied with the doctor because of communication (I had better communication with my previous doctor in pediatric care).
- Lost medical files when being sent to new hospital. No communication with me.
- The new hospital didn't know anything about my history and everything was unclear
- Less attention

#2

16. Would you do anything differently? - Yes

- Smoother change. Someone making sure everything will be ok once transition is complete. Someone telling the young patient how things will work and to tell they will be receiving good treatment.
- There was no transition phase, I just stopped seeing my pediatric doctor and started seeing the new one. Maybe a gathering with my old and new doctor would have been nice.
- I would chose another doctor and hope he would better.
- That there is a systematic reception and accompaniment of the adolescents who arrive in the adult services
- I'd have tried to find a better team
- More in "soft", can be someone to advise / accompany
- Swap hospitals quicker (took 6 months)
- Do my own research earlier as to which hospital I wished to move to and not relied on the existing hospital's opinion
- I'd make sure I was already registered with the IBD nurse at least
- I would wait until my private health insurance covers me in a private hospital (it kicks in this October)
- I'd research more on peoples experiences
- Transition sooner than i did (transitioned 19)
- Go to a better hospital
- I will avoid being taken care of in a small field hospital that has neither the treatments nor the knowledge for this type of disease.
- Change medicin earlier
- I would like to find another care center
- Don't go to doctors , no one can help me right. Centre 's also stupid
- Research, seek support, further information etc.
- Have a joint Eua with both my old surgeon and adult surgeon but this was unable to be done due to them both having busy schedule
- I would get information about the other specialists available in the area I moved to
- I would be more persistant in meeting and deciding who will be my new doctor before i transitioned.
- Start the transition before (moved to college)
- The new doc told my to stop taking my meds, i would not do that today
- Move to another country
- The hospitalitation
- I would ask for a list of names and numbers that might be useful to me.
- Have more involvement, do research, chose a different hospital
- I would choose different doctor.
- Change hospital, this one is not very good
- More info about different clinics
- Even will go before the time i did transferred
- Asking to still be in child care at the hospital for a while until I was feeling better
- Push to know all the services provided

- change the doctor sooner