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A JOINT MDT CLINIC MAY IMPROVE ADHERENCE TO SURGERY IN ADOLESCENTS AND YOUNG ADULTS (AYA) WITH REFRACTORY TO MEDICAL TREATMENT INFLAMMATORY BOWEL DISEASES (IBD)

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Objectives IBD is a chronic inflammatory disease of the GI tract which in 25% of cases presents in the paediatric age group and the incidence continues to increase,¹ suggesting a great proportion of patients will need to transition between paediatric and adult services. Transitioning patients have been shown to engage less well to healthcare services and may struggle with adherence.² Moreover, paediatric IBD may be aggressive and refractory to medical management, necessitating surgical therapy that can be extensive and body deforming such as the formation of an ostomy.

The physical and psychological impact of such a surgery to the AYA can be overwhelming, making the appropriate approach by the healthcare team enormously crucial although equally challenging.

We developed a structured multi-disciplinary (MDT) based pathway for AYA patients who suffer from debilitating and refractory to medical treatment IBD that necessitates surgery and aimed to measure patients' acceptance and eventual adherence to the recommended surgery.

Methods Patients with refractory IBD and ongoing IBD related symptoms were discussed in the IBD MDT. Where medical therapy had failed, AYA patients were referred to the adolescent joint IBD clinic. The joint IBD clinic consists of a face to face appointment with an adolescent IBD gastroenterologist, an IBD colorectal surgeon and a specialist IBD surgical CNS as well as direct access to an adolescent IBD dietician. During the appointment, AYAs and their carers have the opportunity of a thorough discussion on their symptoms, nature and phenotype of their disease and the rationale and details of the recommended surgery. The CNS connects them with other patients with similar types of surgery and acts as a direct point of contact throughout their time of comprehension and decision making.

Results From January 2020 to June 2022, 38 patients between the age of 14 and 22 years old were referred to the joint IBD adolescent clinic for a recommendation of a surgery. 7 (18%) had refractory ulcerative colitis and the rest had refractory Crohn's disease. The majority of patients (7 with UC and 18 with refractory colonic and perianal Crohn's) would need to have a potentially lifelong stoma bag following the operation whereas the remaining patients were also consented for a risk of a stoma formation. 16 patients (42%) needed to have more than one joint consultation prior to making their decision.

32 (84%) patients adhered to the recommended surgery even though importantly the majority of patients (26; 69%) were averse to this before initially coming to the clinic.

Longer term outcomes of those patients are being prospectively measured.

Conclusions Our cohort of young complex IBD patients adhered to the recommended surgery to a significant percentage of 84%. A structured MDT approach we believe helped in establishing trust between the young patient with IBD and the healthcare team and promoted patients' engagement to healthcare services, hence an initial refusal of surgery was

significantly converted to acceptance. More data on patients' views through satisfaction forms will provide additional information on how to further improve transitioning services.

REFERENCES

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YOU'RE STILL WELCOME VIRTUALLY

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Objectives The COVID-19 pandemic accelerated the adoption of virtual solutions to enable continuity of health services for those with acute or long-term medical conditions. Doctors needed to rapidly change their ways of working to continue to provide good access to health care via in person appointments, phone or video consultations.¹

Organisations such as NHSE and RCGP rapidly produced guidance to support professionals in the principles of safe video consulting, however these did not fully explore the issues which more pertinent to children and young people, including access, consent and confidentiality, or potential safeguarding risks including those associated with virtual examinations, receiving, capturing and storing images.^{2, 3} The YPHSIG worked with interested organisations to produce a statement to raise these issues with clinicians but there was still a gap in the information available for children, young people and their families.^{4,5} RCPC &Us COVID Book Club, a youth led project on life in the pandemic, also identified that there was a need for clear information about accessing online or phone appointments.^{6,7}

Methods Doctors from RCPC, RCGP, RCPsych and BASHH worked with young people from Central Beds Youth Voice and RCPC &Us to create a leaflet for young people.⁸ Initial drafts, produced by clinicians and informed from COVID Book Club, contained large amounts of information, but with the help of young people who said '*It's too long, it needs to be shorter, colourful and really clear to understand*'⁹ it was refined and key messages teased out. The design ideas provided by young people were then taken forward and the final leaflet produced.

Results The two-page leaflet has been widely publicised and well received. Young people involved in the work said '*This is so much better than the first version, I think it'll help people my age loads, it's great to see things changed from what we said before*'¹⁰ Clinicians have said '*Great resource launched by @RCPC_and_Us providing useful information on health appointments for young people*'¹¹

Conclusions The pandemic saw a change in the way health services are offered to children and young people. It is important that the principles of accessibility, patient choice, consent, confidentiality and confidentiality, environment, attitudes, values and safety are as understood by clinicians and children, young people and their families for virtual as they are for in person appointments and this collaborative leaflet will support with this.

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