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| **Digital technologies for Adolescent and Young Persons with Inflammatory Bowel Disease JLA Priority Setting Partnership** | **Total number of verified uncertainties identified by the PSP** **= 45** | **Date of priority setting workshop 24th June 2023** |  |
| **Question rank** | **Uncertainty** | **Explanatory note/original uncertainty** | **Evidence** | **Source of Uncertainty** | **Health Research Classification System** |
| 1  | How can digital technology give adolescents/ young people with IBD, parents and carers easy and understandable access to medical history in one platform to include medical notes, track medication history, track results, generate alerts on abnormal results and book tests? | Record access is well established in a number of countries around the world. An example of this is Sweden which has a national patient portal that provides patients with online services. One of the challenges within some health services e.g. the national health service (NHS) in the United Kingdom is different electronic platforms used in primary and secondary care that are not integrated, and very few patients have access to their electronic health records and results. Many questions were generated from the stakeholders regarding this area of digital health technology.*‘’Could I see any test results on there?’’**‘’Online access to test results’’**’Technology to see blood results’’**‘’Can digital apps help get tests or results faster?’’**‘’I would like to know if technology could help me get my test results faster‘’**‘’Would using technology and apps help me get test results quicker?’’**’’Apps where you can see test results quicker’’**‘’Would patients get quick access to test results digitally?’’**‘’Can test results be obtained quicker?’’**‘’Can technology be used to give me my test results quicker?’’**‘’Can the technology help me get test results faster?’’**‘’Test results faster, in one place and easily accessible with advice to explain the results in clear English’’**’I would like to see technology that allows young people and carers to access test results* *faster and therefore be more able to self-manage IBD’’**‘’Is there an app to get results from IBD tests?’’**‘’Will results from regular blood testing be on there?’’**‘’I'd like easier access to blood test and other test results rather than ringing IBD nurses and waiting around. Also a way to* *keep a record of blood tests and see any changes.’’**‘’Within an app, have the possibility of recent up to date blood results etc, so I can monitor and track my own health and if lacking in certain vitamins.’’**‘’Is it possible to have an app where when a routine blood test is done the patient and carers can be notified of their inflammation levels or areas which needs attention?’’**‘’Will results from poo tests be on there?’’**’’Single click access to patient results (faecal calprotectin trends etc)’’**‘’I would like to be able to access the results of my tests and blood results from an app on my phone without having to constantly contact my nurse specialists to find out any changes in the results’’**‘’Similar improvement in IT so that scan results are automatically sent and downloaded via an electronic portal, with alerts about unexpected results etc.’’* *‘’Will this type of Technology gives access to seeing MRI results?’’* *‘‘’A way to view results, such as blood tests, faecal calprotectins, MRI's, colonoscopies etc in one place, that could also be used to fulfil the test requests at different hospitals and GP, I struggle to get our local hospital and GP to accept my daughter's samples if not specifically requested and written on their system.’’**‘’Hospital to send blood/faecal test forms digitally to prevent waiting for them in the post or battling with GP reception’’**‘’Booking of routine blood tests, reordering meds, etc’’**‘’Many times I’ve taken notes in on my phone of the medication my daughter is on. It would help if it was all on an App’’**‘’Being able to view my son’s medication etc online in the same way as I can my own would be helpful - a linked profile?’’*‘*’Access to results using technology is important however how can this be supported by factual information about what these actually mean?’’**‘’With regards to test result question, do they also want to understand what their results mean in the context of their condition?’’**‘’How could an app make the results clear enough to understand if you are not aware of medical jargon?’’* | None identified | 16 parents/carers11 adolescent/ young people with IBD4 healthcare professionals | Oral and gastrointestinal |
| 2 | How can digital technology make it easier for adolescents/ young people with IBD to communicate with their regular nurse or doctor to signal the need for help including help with mood and emotions? | Common questions from stakeholders related to methods of improving the communication between patients, their carers and their IBD team. *‘’Can digital technologies improve the response time for support when symptoms change from the IBD teams?’’**‘’How apps can help report wellness to IBD doctors?’’**‘’How will the app help report wellness to the doctors?’’**‘’How can apps help report wellness to doctors of IBD patients?’’**‘’Instant messaging is a good idea but could put extra strain on IBD teams, maybe just to know that your communication has been received/acknowledged and that a message/email will be sent as soon as possible.’’*‘*’It is almost impossible to get an psychologist for support for young adult going through IBD?’’* | None identified | 3 adolescents/ young people with IBD3 parent/carers | Oral and gastrointestinal |
| 3 | Can a single digital platform be used within national health services so that medical information for adolescents/ young people with IBD, can be shared between different healthcare teams including GPs? | A lack of integration of primary and secondary care electronic platforms within health services, for instance in the UK national health service (NHS), has resulted in perceived service inefficiencies and dissatisfaction in patient care. This was highlighted in questions derived from patients, their carers and health care professionals.*‘’Can digital technology provide a standardised national platform for disease monitoring?’’**‘’Do we have the ability to deliver a UK-wide IBD patient management system?’’**‘’We need to encourage regional centres to use the same digital technologies across a network. This will support tertiary centres to manage rollout of technologies and support patients in a manageable way.’’**‘’Is there a way to have a centralised place for test results and documents and medications from my hospital?’’**‘’Prior to utilisation and implementation of specific IBD technologies, would it not be more urgent to enable access across regions to blood monitoring systems e.g. ICE, to improve patient care and service efficiency? i.e. so a tertiary centre can request and access blood and stool results, even imaging, across the regions they cover.’’**‘’Need a technology that links in with the hospital portal, so that communication becomes part of their health care records’’**‘’Will my hospital be able to adequately support this digital platform?’’**‘’Could we use digital technology to communicate results with GPs and vice versa?’’**‘’How can digital stop us having to get blood tests at the doctor and then us having to ring up, go and get a print out of the results, scan them and email them ourselves to the IBD team at the hospital, chase up whether they are ok and chase the next medication prescription that has to be dispatched from the hospital pharmacy by special delivery? It is very convoluted and at risk of human error/absence that can stop in tracks and stop medication being available in time’’**‘’Instant link between GP blood results, IBD team, consultant etc to have quick collaboration and information plus fast update on any areas of concern or just to be**able to swiftly get next medication prescription without multiple visits and emails.’’**‘’Shared access between GP and consultants on what is happening with treatment and responsibilities. Maybe an app that can be shared by everyone involved in the care including the patient.’’**‘’NHS consultant e-consult would be useful for serious ongoing conditions. Discharged from care on prognosis of healing, yet when it doesn’t happen, it remains a surprise to GP and consultants, who don’t follow up, no alerts are pushed to them an issue still exists, that recovery isn’t as planned, MRI requested by them still hasn’t happened etc. GP has no idea what to* *do anyway, but remains gate keeper to healthcare.’’**‘’A link with NHS records and ability to record/monitor recovery (lack of) or new issues would be great, such that medical professionals are alerted to at least review. We have completely learnt through this, to expect NHS communication to be broken at every level. Why don’t medical professionals track recovery progress against expectations? Every other task has equivalent project management/data driven type mechanisms. But for something so serious, nothing.’’**‘’It would be helpful to have an app/software that can merge blood tests and investigation results irrespective of where they are taken, so the IBD team can directly access the results of investigations performed locally etc.’’**‘’Joined up records from England and Wales would help.. lots of results not available between wales and England when being seen in tertiary centres’’**‘’Is a university student able to have their blood tests done at a local university GP and the results sent electronically to their IBD team at the hospital local to their family home?’’**‘’There seems to be disjointed care when it comes to university students. IBD teams cannot liaise with university GPs if they are under different trusts’’**‘’Lack of recovery, means continued ‘fit notes’ are needed. GP’s are somehow surprised and need to be prompted via e-consult that an extension is needed. If comms weren’t broken, they’d be aware their patient is still unfit, undergoing daily treatment at their surgery, long after recovery predicted. Fit notes would be extended on time as they are aware!’’* | None identified | 8 parents/carers7 health care professionals3 adolescent/ young people with IBD | Oral and gastrointestinal |
| 4 | How can digital technology help adolescents/ young people with IBD with home testing and monitoring e.g. bloods/stool? | Point-of-care and home stool testing kits are now available for monitoring treatment response in IBD patients. Key uncertainties around the technology related to their use in adolescents and young people with IBD, within healthcare and their long term clinical impact.*‘’We need to develop methods for disease monitoring remotely e.g. home calprotectin and home blood monitoring’’**‘’Is there any mobile technology being looked in to for recording levels of testing such as stool samples? This could save a trip to the hospital.’’**‘’I would like to know if technology can be used to conduct certain tests more easily and quickly, e.g. for calprotectin, a home test that also provides the results in e.g. an app?’’**‘’Using technology at home (apps) to monitor calprotectin levels’’**‘’Is there any kind of digital technology being developed to manage the day to day health symptoms, stages, severity of the illness like the finger prick for diabetes?’’**‘’I want there to be a way we can monitor our disease activity and this is sent to the hospital automatically‘’* | Available evidence that partially answered the summary question:Yin AL, Hachuel D, Pollak JP, Scherl EJ, Estrin D. Digital Health Apps in the Clinical Care of Inflammatory Bowel Disease: Scoping Review. J Med Internet Res. 2019 Aug 19;21(8):e14630. doi: 10.2196/14630. PMID: 31429410; PMCID: PMC6718080. | 4 parents/carers1 adolescent/ young person with IBD1 healthcare professional | Oral and gastrointestinal |
| 5 | Can digital technology make it easier and quicker to diagnose adolescents/ young people with IBD? | Most patients undergo a number of investigations before diagnosis including invasive procedures such as endoscopy. Some patients experience a delay in their diagnosis. Questions proposed by adolescents and young people with IBD relate to whether digital technology could simplify the diagnostic process and shorten the diagnostic pathway.*‘’Could technology be used to diagnose me quicker and help me to understand the disease better?’’**‘’Is there scope for technology to aid in diagnostic processes? For example, having capability for a patient to go through questions to identify symptoms and not patterns, and have an app or similar interface that uses this information to narrow down the likely diagnosis and suggest the next steps?’’* | None identified | 2 adolescents/ young people with IBD | Oral and gastrointestinal |
| 6 | How can digital technology help adolescents/ young people with IBD to feel more in control and independent with their IBD? | Paediatric patients will continue to require medical care as they mature into adults. In chronic disease, skills and behaviour in health maintenance are expected to develop over time. Common questions from stakeholders relate to how digital technology could improve independence with disease management. *‘’Can use of apps/technology promote independence and feelings of control over a young person’s own diagnosis?’’**‘’Can apps providing information, regular assessments and reminders improve adherence to IBD medication in young people?’’**‘’Apps to remind teenagers to take their medication’’**‘’An app to track food/symptoms and provide medication reminders could be useful’’**‘’Could the technology support independence when it comes to medication?’’**‘’Could self-care/advice type apps even link with appointment making tech so can book appt e.g. for bloods or pharmacy to get more meds?’’* | None identified | 3 healthcare professionals2 parents/carers1 adolescent/ young person with IBD | Oral and gastrointestinal |
| 7 | Can digital technology support healthcare for adolescents/ young people with IBD when they move from the children’s team to the adult team and can this improve patient experience? | Moving between paediatric and adult care (transition) can be a difficult time for young patients. Early education about the transition process and equipping patients with self-management skills are important for fostering independence for managing life with chronic disease.*‘’Transition’’**‘’Transition readiness/wellness in different areas’’**‘’What role can digital technology play in supporting young people make the transition to adult care?’’**‘’Would there be particular digital technology resources aimed at the transition period to adult IBD care?’’* | None identified | 3 healthcare professionals1 parent/carer | Oral and gastrointestinal |
| 8 | How can digital technology help adolescents/ young people with IBD to feel supported with their care when they are first diagnosed? | Many newly diagnosed patients with IBD experience many physical, mental and social uncertainties whilst coming to terms with a chronic illness. *‘’What role can digital technology play in supporting young people who have recently been diagnosed?’’* | None identified | 1 parent/carer | Oral and gastrointestinal |
| 9 | How can digital technology be used to allow adolescents/ young people with IBD to contact the IBD team and other healthcare professionals in a timely manner? | Most IBD services provide an IBD advice line to their patients which allows them to access support from the team of Specialist Nurses. Common questions relate to whether digital technology can foster faster access to the IBD team.*‘’Can digital technologies improve the response time for support when symptoms change from the IBD teams?’’**‘’Access to healthcare teams to help with symptoms as they are happening rather than* *discussing it with a doctor/advice line after you’ve been suffering.’’**‘’Would the responses on a digital messaging service be faster than emailing?’’**‘’How fast would the response from the medical professional be?’’**‘’Would treatment of IBD be quicker and easier if it was digital?’’**‘’Would technology help get appointments, advice, treatment faster?’’* | None identified | 3 adolescent/ young people with IBD2 parents/carers1 healthcare professional | Oral and gastrointestinal |
| 10 | How can we make sure that big data generated by different digital technologies collect similar types of information so that it can be brought together to study long term impact in a real world setting and measure outcomes for young people with IBD? | Advances in digital technology has led to availability to a wealth of real-world data which has improved understanding of clinical outcomes and facilitates drug approval and post-marketing surveillance. Digital health technologies generate a wealth of data but for this to be put to good use it needs to be consistent and comparable. Collation of data from several sources offers value to understand and improve the management of patients and newinsights for research.*‘’With so many different digital technologies can we harmonise the type of data collected so we can collate outcomes from different sources to study the long term impact of interventions in a real world setting’’**‘’How can data from disease registries (EUROKIDS, UK IBD registry) be utilised to improve outcomes for CYPs with IBD?’’* | None identified | 2 healthcare professionals | Oral and gastrointestinal |
| 11 | How can digital technology make it easier for adolescents/ young people with IBD to access and share their health documents and results? | Data flow across health services may be fragmented. A number of stakeholders highlighted the importance of patient access to their own health records to facilitate movement of health information alongside their health journey. *‘’A digital app that is personal to the patient. It should hold all records with regards to patient related information - from day of diagnosis.Colonoscopy/histology/medications trialled. Also records the usual pre-immunosuppressive screening tests’’* *‘’I would like to have proper access to my records, blood results, endoscopy results etc. I want to access them from any trust and GP practice.’’**‘’A detailed history available to view all* *doctor's notes, results and findings as well as prescriptions - easy to share medical history when travelling’’**‘’Can a person's health summary be safely recorded for their own access to improve their understanding of their health journey and facilitate transfer to care services wherever they are e.g. for work/ training/ travelling?’’**‘’I recently discovered Patients Know Best by accident - a really cool digital platform with all of my test results so far. It would be good for similar websites to be more widespread or even integrate in an app?’’**‘’I would like to have access to view my full electronic health record with test results so I can share it with other medical professionals and have all my information in one place.’’**‘’App to document patient journey e.g. diagnosis/extent of disease, medications used and why stopped’’**‘’Is it possible to have online access to a list of all medications including injections and online access to patient notes? This would be especially useful for university students who often have to register with a GP at university but keep their IBD team at a hospital local to their family home’’**‘’Is there an app that allows young people with IBD to access their test results, appointments, etc?’’**‘’Having more info on an App would help with info and appointments to show school and her sport clubs/activities’’* | None identified | 4 healthcare professionals3 adolescents/ young people with IBD4 parents/ carers | Oral and gastrointestinal |
| 12 | How can digital technologies complement or replace diagnostic tests such as endoscopy? | Most patients undergo a number of investigations, including invasive endoscopic procedures, before being diagnosed with IBD. Questions that were proposed were whether digital technology could be used to reduce the need for invasive procedures. *‘’Digital technology, non-invasive, that can help diagnose the disease: ultrasound scans, x-rays’’**‘’Improvement of existing diagnostic and evaluation techniques, making them more comfortable for patients, such as the use of more flexible, thinner, colonoscopy instruments, or the development of less invasive techniques such as the use of pill cameras etc.’’**‘’Technological endoscopy tests that are less intrusive and tolerable by young patients. Can these be developed?’’* | Available evidence that partially answered the summary question:Majidova K, Handfield J, Kafi K, Martin RD, Kubinski R. Role of Digital Health and Artificial Intelligence in Inflammatory Bowel Disease: A Scoping Review. Genes (Basel). 2021 Sep 22;12(10):1465. doi: 10.3390/genes12101465. PMID: 34680860; PMCID: PMC8535572. | 2 adolescent/ young people with IBD1 parent/carer | Oral and gastrointestinal |
| 13 | How can digital technology be personalised to an adolescent/ young person’s symptoms and test results? | Personalised medicine is an evolving research field which centres on delivering more precise diagnosis, treatment and prognosis that is tailored to the characteristics of an individual patient or groups of patients. Digital health technology has the potential to complement this through providing information about the user or improve quality and access to care.*‘’Can apps be designed to be a constant and personalised digital 'companion' something akin to the daemons in the sci-fi story 'his dark materials' adapted to support patients for different stages of disease’’**‘’Digital technology that can match the disease with the perfect treatment for each individual according to his investigation tests results’’**‘’There has been much talk of individualised treatment protocols, could digital technological monitoring of symptoms facilitate research into this?’’* | None identified | 2 healthcare professionals2 parents/ carers | Oral and gastrointestinal |
| 14 | How can digital technology help adolescents/ young people with IBD to track non-IBD related symptoms to share with their IBD team alongside IBD symptoms? | Symptom diaries or logs can offer valuable overview of changes in disease activity and the development of associated conditions in real-time to inform decisions about management. Several stakeholders asked questions relating to how digital technology could help with tracking disease and non-disease related symptoms and how this information could be shared with the IBD team.*‘’As my daughter doesn't have typical Crohn's symptoms I'd like a way to track the symptoms she does have as in her skin. Somewhere where I can keep pictures that myself and her IBD can access’’**‘’For patients, is there a possibility to upload pictures of bowel openings so health professionals can see it, as descriptions tend to be very subjective?’’**‘’Would the apps include more extra-intestinal manifestations like health anxiety, mental health and/or non-typical symptoms - skin rashes, acne?’’**‘’I would like the "other symptoms" of IBD to be available in a platform that faces patients and clinicians. In particular: fatigue, stress, anxiety, HRQOLs, sexual dysfunction. The questions that we want to know about but don't always have the time to ask.’’**‘’Can a symptom record of other conditions be managed and shared?’’**‘’Could an app track growth and hormones changes, and stress versus flares?’’* | Available evidence that partially answered the summary question:Pang L, Liu H, Liu Z, Tan J, Zhou LY, Qiu Y, Lin X, He J, Li X, Lin S, Ghosh S, Mao R, Chen M. 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Inflamm Bowel Dis. 2018 Jun 8;24(7):1453-1459. doi: 10.1093/ibd/izy162. PMID: 29868764.Carlsen K, Jakobsen C, Houen G, Kallemose T, Paerregaard A, Riis LB, Munkholm P, Wewer V. Self-managed eHealth Disease Monitoring in Children and Adolescents with Inflammatory Bowel Disease: A Randomized Controlled Trial. Inflamm Bowel Dis. 2017 Mar;23(3):357-365. doi:10.1097/MIB.0000000000001026. PMID: 28221247.Jackson BD, Gray K, Knowles SR, De Cruz P. EHealth Technologies in Inflammatory Bowel Disease: A Systematic Review. J Crohns Colitis. 2016 Sep;10(9):1103-21. doi: 10.1093/ecco-jcc/jjw059. Epub 2016 Feb 29. PMID: 26928960.Stiles-Shields C, Keefer L. Web-based interventions for ulcerative colitis and Crohn's disease: systematic review and future directions. Clin Exp Gastroenterol. 2015 May 11;8:149-57. doi: 10.2147/CEG.S56069. PMID: 26005356; PMCID: PMC4433044.Aguas Peris M, Del Hoyo J, Bebia P, Faubel R, Barrios A, Bastida G, Valdivieso B, Nos P. 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PMID: 21071584.McCormick M, Reed-Knight B, Lewis JD, Gold BD, Blount RL. Coping skills for reducing pain and somatic symptoms in adolescents with IBD. Inflamm Bowel Dis. 2010 Dec;16(12):2148-57. doi: 10.1002/ibd.21302. PMID: 20848505. | 3 parents/carers2 healthcare professionals1 adolescent/ young person with IBD | Oral and gastrointestinal |
| 15 | Can digital technology platforms make it easier for adolescents/ young people with IBD to connect with similar people within the adolescent/young person IBD community for peer-support and a safe space to talk to each other? | Peer support interventions are one way of providing support to adolescents and young people with IBD. They have the potential to empower individuals through the adoption of coping strategies and self-management skills which in turn enhance confidence and self-esteem. Several healthcare providers and adolescents or young people with IBD asked questions about whether digital technology could provide a safe space to engage woth others within the IBD community.*‘’Online support group/chat via an app you download‘’**‘’There should be an app for kids like Facebook and Instagram where kids can explain how they feel and other people can help them like people who have gone through what they’re going through’’**‘’Creating a safe space for people with the condition to talk to others and discuss tips and struggles. Just have someone to talk to who understands’’**‘’Connections with other people/parents or families who are using diet to help control symptom ‘’**‘’Can digital technology help young people feel less alone/part of a supportive community with their IBD and what impact does this have on their health outcomes?’’**‘’Peer support‘’**‘’Will technology help me interact with others with IBD?’’**‘’Could a social media platform be developed specifically for IBD patients to communicate?’’**‘’How would social media help you with IBD?’’**‘’Ways to connect with people your age and in your area who are going through the same thing’’**‘’A platform to connect with people with IBD’’**‘’Why are there not enough groups/things for young people with IBD to join in online?’’**‘’It would be good to be able to connect better with other young people with IBD or know about events.’’* | Available evidence that partially answered the summary question:Kelso M, Feagins LA. Can Smartphones Help Deliver Smarter Care for Patients With Inflammatory Bowel Disease? Inflamm Bowel Dis. 2018 Jun 8;24(7):1453-1459. doi: 10.1093/ibd/izy162. PMID: 29868764. | 9 adolescent/ oung people with IBD3 healthcare professionals1 parent/carer | Oral and gastrointestinal |
| 16 | Will digital technology be able to predict what happens with an adolescent or young people IBD in the future? | The goal of predictive medicine is to estimate the risk of a future event or outcome based on a range of information from an individual. The advance in technology and tools for data analysis offers potential for developing clinical prediction models to help IBD healthcare professionals and patients make decisions about care. As IBD is a chronic disease, there is value in predicting disease course and outcomes in adolescents and young people with these conditions.*‘’Does digital technology help in accurately predicting the prognosis?’’* | None identified | 1 healthcare professional | Oral and gastrointestinal |
| 17 | How can wearable technology keep adolescents/ young people with IBD well? | There is growing availability of wearable technology, also known as ‘’wearables,’’ which electronic devices that can be worn or carried on the body. They are designed so that the user’s personal or physiological data can be monitored and measured through smart sensors embedded within the device.*‘’How would wearable technology help in regulating the disease?’’**‘’Is there a role for wearable technology to keep patients with IBD well?’’* | None identified | 1 adolescent/ young person with IBD1 healthcare professional | Oral and gastrointestinal |
| 18 | How can patients link fitness and diet apps with IBD digital technology to identify patterns in symptoms? | Lifestyle and dietary factors may have a role in the onset of IBD and precipitate symptoms in some patients who have been diagnosed already. Dietary therapy can also be used for active disease in adolescents and young people with Crohn’s disease. Therefore, digital technology such as apps could be a useful adjunct to the management of patients in this age group for symptom and disease monitoring. *’There's a good app for girls to track their periods/symptoms related to their reproductive system to spot patterns etc and there’s a live bot that starts a chat when an unusual symptom is logged. Something like this might be helpful to keep track of daily IBD symptoms and stress levels and what food may have triggered a bad day etc. It would also be beneficial for gastro nurses/ nutritionists to spot patterns and give advice. I feel this would be beneficial to me and easy to keep track of my symptoms.’’**‘’Is there scope for integration between an IBD-focused technology and other existing technologies? For instance, could data starting and analysis be facilitated between apps like MyFitnessPal such that users may be able to see correlations between certain foods and symptoms, same with fitness apps to see if exercise has any correlation; same with fasting apps etc?’’**‘’How to use broader data to spot trends that help manage Crohn’s?’’* | None identified. | 2 adolescent/ young people with IBD1 parent/carer | Oral and gastrointestinal |
| 19Question not discussed or ranked at workshop | How can adolescents/young people and their carers learn more about how digital technologies can help with their care? | Digital literacy is important for keeping up with advances in technology which offer new ways of working, studying and engaging with the world. Digital health technology is used in collaboration with patients and requires an understanding of their role, how to operate them as well and the impact that it has on their care. *‘’Are people aware of how digital technology can be used?’’* | None identified | 1 healthcare professionals | Oral and gastrointestinal |
| 20Question not discussed or ranked at workshop | How can we design digital technology to suit different types of adolescents/ young people with IBD and their needs? | Personalisation of digital technology in adolescents and young people with IBD has the potential to increase user satisfaction and promote higher engagement with care. The main concerns from stakeholders relate to the challenges of accessibility, fragmented services and cost when designing person-centred digital health technology.*‘’How to target a wide range of people - not only when unwell/anxious but as routine care for most?’’**‘’Accessibility is a concern as I anticipate this may be a postcode lottery or only be available to those who have insurance. Already I cannot access services due to funding in my area, that my sister in London can.’’**‘’Will digital tech in IBD be at a cost to service user or will it be on the NHS?’’**‘’Is the service going to be free for patients and professionals?’’* | None identified | 2 healthcare professionals2 adolescent/ young people with IBD | Oral and gastrointestinal |
| 21Question not discussed or ranked at workshop | Do digital interventions improve access to underserved groups, and if so, which ones? | Despite widespread adoption of digital technology, equitable use and benefit remains a challenge. Underserved communities may face unique barriers in access and use of digital health technology due to economic, cultural or linguistic factors. Digital technology can make it easier to measure the reach and impact of interventions which can result in targets for service improvement. At present, there is a paucity of evidence as to how digital technology can best serve adolescent and young IBD patients from these vulnerable communities.*‘’Most but not all young people have access to IT: I care for families where there is one family mobile’’**‘’Can digital technologies be used to improve engagement with "hard to reach" groups with IBD?’’**‘’Can digital technology allow us to better concentrate care on patients in most need?’’**‘’I would like my patients to have access to the information available in the CCUK in their own mother tongue - especially for the newly diagnosed patients’’* | None identified. | 4 healthcare professionals | Oral and gastrointestinal |
| 22Question not discussed or ranked at workshop | What types of digital technology do adolescents/ young people with IBD prefer? | Patients have varied opinions about digital health technology. Understanding the preferences and attitudes of patients ensures that the development and implementation of digital health technology for adolescents and young people with IBD is appropriate and patient-centred.*‘’Is it likely that technology e.g. medical apps, could be available in smaller devices such as smart watches?’’**‘’Would it be a mobile app?’’****‘****’How would we access these technologies?****’’****‘’How do young people want to use technology in their healthcare interactions?’’* | None identified | 4 adolescent/ young people with IBD1 healthcare professional | Oral and gastrointestinal |
| 23Question not discussed or ranked at workshop | Who would benefit most from using digital technologies for IBD? | Digital health technology has enhanced operational efficiency in medical care and improved patient medical records. For adolescents and young people with IBD, it is unknown which patient groups would gain the most short and long term benefits from digital technology.*‘’Which patients do well with digital technology? Not all people will like it.’’**‘’I believe technology to enhance care is so important but, with youngster specifically, it has to be as part of a wider support package where the voices of both the IBD patient and their parent/carer can be heard.’’* | None identified | 1 healthcare professional1 parent/carer | Oral and gastrointestinal |
| 24Question not discussed or ranked at workshop | How can we encourage people to adopt and use digital technologies as part of their ongoing IBD care? | Adolescent and young people with IBD are uniquely positioned to understand the opportunities and challenges of digital technology due to early experience with their use. Understanding reasons for adoption and engagement with digital health technologies can ensure that their development is relevant, effective, safe and meets the needs of this age group.‘*’Is video consultation actually a useful tool with children and young people or does it lead to them being excluded from the conversation? (My experience is that teens turn off cameras and try their best not to engage with adults via video.)’’**‘’What is the best way to incorporate the digital world in everyday clinical practice so that healthcare professionals have designated the time to interact with young people and a time that is best for them where they don’t have to interrupt schooling or work?’’**‘’Self-care/advice type apps - can these be made to work well enough/user friendly enough?’’**‘’Apps rely on the users diligence. They are only as effective as the data inputted.‘’* | None identified | 2 parents/carers2 healthcare professionals | Oral and gastrointestinal |
| 25Question not discussed or ranked at workshop | Which types of digital technologies lead to better well-being and health for adolescents/ young people with IBD? | Knowledge about the challenges and opportunities offered by digital technology has expanded. Questions remain as to how to identify the right technology for adolescent and young people with IBD, how they can be integrated into care and whether they improve patient satisfaction and long term outcomes. *‘’Does digital technology improve patient outcomes?’’**’’Can digital technology improve the quality of life for young people with IBD?’’**‘’Do patient self-management apps help improve quality of life?’’**‘’Does the use of IT help improve disease control and outcomes?’’**‘’Can technology reduce risk of hospitalisation?’’**’’What is the impact of digital technologies in improving IBD outcomes (hospitalisations for example)?’’* *‘’How can technology help?’’**‘’How does this plan on making a difference?’’* *‘’What is the patient experience with this?’’**’’Does digital technology improve the patient experience of IBD care? (sub questions would include what aspects of digital technology enhance this experience)’’**‘’What type of digital technology use can impact on patient outcomes?’’* *‘’Will patients feel comfortable using technology to report changes in their condition rather than consultations?’’* | None identified | 9 healthcare professionals3 adolescent/ young people with IBD | Oral and gastrointestinal |
| 26Question not discussed or ranked at workshop | What are the possible negative effects on adolescents/ young people with IBD who choose not to engage with digital technologies? | Various factors can influence digital inclusion and engagement with technology in adolescent and young people. These include personal, situational and environmental factors such as lack of motivation or access to internet services. Lack of engagement and accessibility with digital technology may limit the opportunities, support and services for patients although it is currently unknown whether there is an impact on clinical outcomes in this setting. It is therefore important to gain a better understanding of these contributory factors when implementing digital transformation in the care of adolescents and young people with IBD to reduce barriers in engagement with the service. *‘’I worry that the patients that don't engage will get a poorer service’’* | None identified | 1 healthcare professional | Oral and gastrointestinal |
| 27Question not discussed or ranked at workshop | What are some realistic expectations that digital technologies can help adolescents/ young people with IBD and their carers with? | Consumers have increasing expectations of services including healthcare encounters which is likely to vary between individuals. Whilst the health service is becoming more digitalised, the pace of transformation may not be aligned with the demands of adolescent and young people with IBD who may not realise the limitations of digital healthcare.*‘’Will my patients end up having unrealistic expectations from this technology?’’**‘’Do patients realise that using digital technology does not necessarily mean they will have access to healthcare advice in real time?’’* | None identified | 1 healthcare professional1 member of organisation or charity | Oral and gastrointestinal |
| 28Question not discussed or ranked at workshop | How can new digital tools for adolescents/ young people with IBD be created, tested and checked for how accurate they are? | Although many forms of digital technology have been assessed and investigated, there should be continual evaluation of new technology in future research in order to update the evidence base. There are currently no internationally agreed standards or regulatory measures that should be applied during the development of digital health interventions to ensure reliability, safety, confidentiality and protection of personal information. This was more of a concern for health care professionals and parents or carers. *‘’How to develop, test, validate and implement a Digital App to monitor the physical, mental, psychological and well-being domains of IBD care in Adolescent and Young Persons’’**‘’How to develop, test, validate and implement a Home Stool Faecal Calprotectin measurement system for AYP with IBD’’**‘’Can we create quality standards for digital technologies so that technologies including apps that do not meet standards with poor benefits or misinformation are discouraged. This will help to guide developers, when establishing new apps, and patients as to which are the most reliable and helpful apps. This will follow the current initiative in Quality standards for online internet information.’’**‘’Is the information available evidence based and nationally standardized’’**‘’What new digital technology is currently in development for IBD?’’**‘’What type are digital apps are out there for IBD’’**‘’How can we provide a platform that patients will realistically use, but doesn't compromise confidentiality’’**‘’How can the security of the technology be ensured as the information is so personal?’’**‘’Is the governance structure supporting the use of tech in patient care sufficiently robust to protect both patients and their doctors’’**‘’Would some sort of back-up be available should the app fail? For example if data has been recorded over a period of time, would this all be lost?’’**‘’There are always concerns with any digital technology regarding privacy of medical information, this needs to be guaranteed.’’* | Available evidence that partially answered the summary question:Gerner M, Vuillerme N, Aubourg T, Messner EM, Terhorst Y, Hörmann V, Ganzleben I, Schenker H, Schett G, Atreya R, Neurath MF, Knitza J, Orlemann T. Review and Analysis of German Mobile Apps for Inflammatory Bowel Disease Management Using the Mobile Application Rating Scale: Systematic Search in App Stores and Content Analysis. JMIR Mhealth Uhealth. 2022 May 3;10(5):e31102. doi: 10.2196/31102. PMID: 35503246; PMCID: PMC9115651.Nguyen NH, Martinez I, Atreja A, Sitapati AM, Sandborn WJ, Ohno-Machado L, Singh S. Digital Health Technologies for Remote Monitoring and Management of Inflammatory Bowel Disease: A Systematic Review. Am J Gastroenterol. 2022 Jan 1;117(1):78-97. doi: 10.14309/ajg.0000000000001545. 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| 29Question not discussed or ranked at workshop | What problems might arise by shared access to digital technology information with parents/carers and how can access to data generated by digital technology be controlled to share or restrict information with parents/carers? | It is critical that clinicians and healthcare professionals understand the issues surrounding patient autonomy and confidentiality when communicating through digital technology. Adolescent and young people may have different attitudes about sharing sensitive or non-sensitive information with their parents or carers. There is currently little understanding of the impact of shared digital technology use on the relationship between young patients and their parents or carers as their self-management skills are acquired over time. *‘’Young people should get to see the results from MRI, colonoscopy etc. not the parents or guardians.’’**‘’Where can I view all my test results and future treatments all in one place that I can access without asking my parents? I'm 12 years old and the appointment confirmations don't come via post addressed to my parents’’**‘’Will there be an app for parents and children separately or together so both have access at all times?’’**‘’Teenagers often don’t want an app about IBD on their phone, how can we get around this. Is parent reporting reliable?’’* | None identified | 2 adolescent/ young people with IBD2 parents/carers | Oral and gastrointestinal |
| 30Question not discussed or ranked at workshop | Is digital technology better for ulcerative colitis (UC) or Crohn’s disease (CD) in adolescents/ young people with IBD? | Crohn’s disease (CD) and ulcerative colitis (UC) are two distinct disease entities with the presentation and disease course varying depending on the location of the disease. Ulcerative colitis only affects the colon whereas Crohn’s disease is a transmural disease affecting any part of the gastrointestinal tract and is associated with stricturing or penetrating complications. As such, it is currently unknown whether digital technology would benefit specific IBD disease types and whether they should be designed with these in mind. *‘’Is digital technology better for UC versus CD patients’’* | None identified | 1 healthcare professional | Oral and gastrointestinal |
| 31Question not discussed or ranked at workshop | Can digital technology give adolescents/ young people and their carers information about food and diets as well as a personal diet plan? | Diet has a role in triggering symptoms in IBD and many patients believe that food is as important as medication for symptom management. Functional gastrointestinal symptoms can coexist alongside IBD and it can be difficult to distinguish between the two. Adolescent and young people with IBD may modify their diet significantly after diagnosis which can have an impact on their lifestyle and social life. Common questions asked relate to whether digital technology can personalise dietary advice or help patients in their food choices to avoid unnecessary restrictions. *’’Are there any specific diets I should follow?’’**‘’Can apps help with tailoring vague nutritional guidance into specific plans for individuals with IBD?’’**‘’Digital technology that can give advice on best diet according to an individual's test results’’**‘’An app that shows us what we can eat when following the benzoate free diet. This isn't as straightforward as some other diets.’’**‘’I would like to know if there could be an app that I could put my specific dietary restrictions into and it would give me meal/food ideas’’**‘’It would be great to see if technology can be used to provide individualised advice online when possible regarding e.g. diet or other factors that may be influencing the management of IBD. Perhaps a partially AI driven service, partially live professionals on appointment online’’**‘’The app can also have links to dietary advice especially regarding low finer food and ready meals - with possibility of scanning a barcode for advice’’* | None identified | 3 adolescent/ young people with IBD3 parents/carers1 healthcare professional | Oral and gastrointestinal |
| 32Question not discussed or ranked at workshop | How can digital technology educate the IBD team to clearly explain information about IBD and treatments to adolescents/ young people? | Staff training helps to engrain the necessary behaviours, attitudes, skills and knowledge to deliver high quality and safe care to patients. Interactions with adolescents and young people with IBD may require additional communication skills compared to adults patients. Therefore educational strategies should be tailored to the developmental needs of adolescents and young people with IBD.*‘’Train health professionals to explain medications and treatment in plain English, is this possible?’’* | None identified | 1 parent/carer | Oral and gastrointestinal |
| 33Question not discussed or ranked at workshop | How can digital technology help adolescents/ young people with IBD, their carers and friends to understand more about treatments and surgery in IBD? | Digital technology can offer multiple ways of delivering education to patients and their parents or carers. Patient and parental health literacy can facilitate interactions from the IBD team and enhance their involvement in decision making and empower adolescents and young people with IBD. Specific needs for health information can remain unmet as it needs to be provided at the appropriate time, be accessible and be available as many times as it is required. *‘’Are there apps where you can track symptoms, find answers to questions I may have without having to contact the hospital team?’’**‘’Can digital information be more appropriately signposted for frequently asked questions e.g. about self-management, drug info, other patients experience with similar health conditions as short video/ animation/ podcast?’’**‘’We would like it to be made more easier to access specific information using digital technology. Often we need to look through multiple pages to find answers.’’**‘’An information app that could be updated as needed with quick access info that can't always be accessed out of hours or you don't trust from the internet, such as an issue with meds that is not an emergency but you need to know how to store it correctly.’’**‘’My daughter is 10, good to learn more**about UC and IBD in young children.’’**‘’Could a digital platform be used to explain IBD to people and the symptoms to friends, families, schools etc. to support a person better?’’**‘’Can apps/technology help young people’s family and friends understand IBD by sharing data from symptom tracking apps?’’**‘’Is there an app to show my family what it’s like to have a stoma?’’* | None identified | 4 adolescent/ young people with IBD3 parents/carers1 healthcare professional  | Oral and gastrointestinal |
| 34Question not discussed or ranked at workshop | How can digital technology help adolescents/ young people with IBD learn more about new IBD treatments in specific situations e.g., in pregnancy, just after diagnosis, and for pain management? | Patient education is key to patient engagement by supporting and enabling adolescents and young people to manage chronic disease as well as plan around challenges that may occur in their lives such as pregnancy, travelling and the availability of new IBD therapy.  *‘’How newer treatments/information are shared amongst patients’’**‘’Are there any new treatments from people with IBD?’’**‘’Can digital technology help with information and new treatment options for my condition?’**’Can we please have provision of online information about a new diagnosis so we are not looking through Google?’’* *‘’Travel advice when patient has IBD’’**‘’Pregnancy advice and biologics’’* | None identified | 3 healthcare professionals2 adolescents/ young people with IBD1 parent/carer1 family member | Oral and gastrointestinal |
| 35Question not discussed or ranked at workshop | How can digital technology help adolescents/young people with IBD and their carers to learn more about diet and lifestyle in IBD and alert them if there are new updates? | There are many lifestyle aspects that are of interest to patients as means to reduce their symptoms and the burden of disease. *‘’What can I do in my day to day life to help improve my condition?’’**‘’Could an app or similar interface help provide practical advice and updates on controllable factors, like diet and lifestyle? The app Zero (for fasting) provides regular, user-friendly summaries of research relevant to the area - perhaps something similar could be done to share growing IBD knowledge. Other practical steps could be helping users locate public bathrooms to help manage symptoms.’’* | None identified | 2 adolescent/ young people with IBD | Oral and gastrointestinal |
| 36Question not discussed or ranked at workshop | How can digital technology help adolescents/young people with IBD and their carers be more aware of research and how to get involved? | There is interest, from both patients and their carers, in obtaining information about current research in IBD and involvement in the recruitment process for studies. *‘’The findings and results of research’s regarding IBD’’**‘’Where to find information on up to date trials that you can put yourself forward for?’’**‘’Alerts to participate in research’’* | None identified | 2 adolescent/ young people with IBD1 parent/carer | Oral and gastrointestinal |
| 37Question not discussed or ranked at workshop | How can personal information from digital technology link to hospital records? | Although digital health technology has the potential to transform patient care, concerns persist relating to patient privacy and data overload when integrating patient information into existing electronic health records. To ensure interoperability, data mut be structured, standardised and be clinically relevant. *‘’How can we ensure patient collected digital data integrates with hospital/primary care collected healthcare records?’’* | None identified | 1 healthcare professional | Oral and gastrointestinal |
| 38Question not discussed or ranked at workshop | Will the use of digital technology create more work for the IBD team and if so, how can this be managed? | Digitalisation of patient care is intended to improve efficiency and improve safety however it remains unclear whether digital technology can create more work burden for staff. Varying digital literacy, availability of resources and data input could contribute to unequal distribution of work.*‘’I have created an app for remote monitoring but problems were how to change staff working patterns to use it, and of course money!’’**‘’Will this technology generate additional work for the team?’’**‘’Does a portal allowing two-way communication/access to records, blood results, letters/patient info help manage patients or does it lead to too much work for the professional team?’’**‘’Do apps actually make a difference to patient care, if there are not enough medical staff to answer the IBD Flare line phone, how will they cope with an app?’’**‘’How would the quantity of messages be managed by the medical team? Is there a risk they could be inundated by messaging?’’**‘’Can the use of digital technologies such as apps that signpost young people to sources of information have a positive impact on the IBD nursing/healthcare time spent on disease and medication education and adolescent and transitional health discussions and support?’’**‘’Might the person responding to an alert from an app work externally to the hospital that treat and know me well?’’**‘’Who is supposed to provide the instant support and two ways consultation?’’**’’Will there be a designated healthcare worker employed to manage the extra workload form the apps?’’**‘’How often would information recorded be reviewed by a health professional?’’* | Available evidence that partially answered the summary question:Pang L, Liu H, Liu Z, Tan J, Zhou LY, Qiu Y, Lin X, He J, Li X, Lin S, Ghosh S, Mao R, Chen M. Role of Telemedicine in Inflammatory Bowel Disease: Systematic Review and Meta-analysis of Randomized Controlled Trials. 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| 39Question not discussed or ranked at workshop | Do adolescents/ young people with IBD prefer face to face or virtual appointments? | Virtual clinics were implemented during the COVID-19 pandemic to provide a safer option for seeking healthcare without the exposure to infection. There is currently a lack of evidence regarding which consultation modality is preferred in the adolescents and young people with IBD. *‘’Is online appointment a good way of doing appointments?’’**‘’I would like to know if it could be possible to Zoom with consultants for telephone appointment instead as it’s easier to talk face to face.’’**‘’I haven't had any experience of online portal chats but I've had mostly phone calls since my diagnosis. This is helpful as it saves a journey to hospital which can sometimes be very difficult with active disease symptoms, so an increase in video consultations could be helpful going forward.’’**‘’Using digital technologies more often to communicate with health professionals. Due to the nature of the disease, sometimes it is stressful to travel and attend appointments in person, video calls would be much better and less stressful.’’**‘’Do you want more video or telephone consultations?’’**‘’Do patients prefer face to face follow up appointments or video/phone?’’**‘’Video calls have been fab and should continue.’’**‘’Is video consultations a way forward of getting to see a consultant more easily? Especially if you have a long way to travel to hospital.’’**‘’I would like to see the use of more video consultations with consultants especially because of the nature of UC it is sometimes difficult to travel.’’**‘’Easier consultations with my doctors and nurses.’’**‘’Telephone consultations should be replaced with Teams meetings.’’*  | Available evidence that partially answered the summary question:Pang L, Liu H, Liu Z, Tan J, Zhou LY, Qiu Y, Lin X, He J, Li X, Lin S, Ghosh S, Mao R, Chen M. Role of Telemedicine in Inflammatory Bowel Disease: Systematic Review and Meta-analysis of Randomized Controlled Trials. J Med Internet Res. 2022 Mar 24;24(3):e28978. doi: 10.2196/28978. PMID: 35323120; PMCID: PMC8990345.Nguyen NH, Martinez I, Atreja A, Sitapati AM, Sandborn WJ, Ohno-Machado L, Singh S. Digital Health Technologies for Remote Monitoring and Management of Inflammatory Bowel Disease: A Systematic Review. 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| 40Question not discussed or ranked at workshop | How can digital technology be implemented to deliver improvements in IBD service delivery for adolescents/ young people with IBD and their carers? | Innovation in healthcare has made a significant impact in recent years with improvement in patient outcomes. Despite this progress, unmet needs still exist and patient care can be improved further. Embedding digital technology into every day patient care has the potential to improve patient care by improving efficiency of services although questions remain as to how this can be achieved and which modalities are optimal.*‘’How can this help with access and availability to services that can help with QOL in IBD? e.g. dietitian, psychology?’’**‘’How can digital apps help manage IBD?’’**‘’Could we manage/treat this horrible disease with the use of digital technology and how?’’**‘’How can apps support my care?’’**‘’How can electronic patient management systems be best utilised to improve care for CYPs with IBD?’’**‘’I believe technology to enhance care is so important but, with youngsters specifically, it has to be as part of a wider support package where the voices of both the IBD patient and their parent/carer can be heard.’’**‘’Can we improve radiology IT systems to message patients regarding appointment times/ patient centred booking of scans etc.?’’**‘’Can tech make it easier to get appointments that suit me rather than just receiving whatever in the post & having to cancel plans?’’**‘’As an extension of my first questions carers can be notified on the app and set up appointments at both party’s convenience?’’**‘’Weekend treatment (wound packing) is transferred to hospital care. The mechanism for that from GP surgery request often breaks down. Appointment times given to patient only by a unknown telephone call you must take. No voice message, text or email will be sent. Why?’’**‘’How could digital technology make it easier to book appointments? I currently find it really hard to get through to my consultant meaning I am seen a lot later than scheduled.’’* | Available evidence that partially answered the summary question:Knowles SR, Mikocka-Walus A. Utilization and efficacy of internet-based eHealth technology in gastroenterology: a systematic review. Scand J Gastroenterol. 2014 Apr;49(4):387-408. doi: 10.3109/00365521.2013.865259. Epub 2014 Feb 5. PMID: 24494974. | 4 adolescent/ young people with IBD4 parents/carers2 healthcare professionals | Oral and gastrointestinal |
| 41Question not discussed or ranked at workshop | Does digital technology make it easier for adolescents/ young people with IBD to book their own clinic appointments when they need them? | Remote monitoring and tracking of symptoms can be helpful for promoting self-management skills. Patient-initiated follow up (PIFU) means that patients are given the responsibility of getting in touch with the IBD team if they experience a worsening of their condition or require an assessment. The aim is to personalise outpatient assessment and therefore reduce follow-up appointments that are not required when the patient is feeling well resulting in time and cost savings for both patients and the health service.*‘’Patient initiated follow up needs to be embedded in adolescent care to avoid unnecessary impact on school, university and home quality of life’’**‘’How can digital technology support patient initiated follow up?’’**‘’How effective would digital technology be for patient triggered follow up in circumstances where compliance with remote follow up i.e. PROMs completion may be poor. What could be done to overcome this?’’* | Available evidence that partially answered the summary question:Gordon M, Sinopoulou V, Akobeng AK, Lakunina S, Gjuladin-Hellon T, Bracewell K. Remote care through telehealth for people with inflammatory bowel disease. Cochrane Database Syst Rev. 2021 Apr 15;2021(4):CD014821. doi: 10.1002/14651858.CD014821. PMCID: PMC8078277.Gohil S, Majd Z, Sheneman JC, Abughosh SM. Interventions to improve medication adherence in inflammatory bowel disease: A systematic review. Patient Educ Couns. 2022 Jul;105(7):1731-1742. doi: 10.1016/j.pec.2021.10.017. Epub 2021 Oct 15. PMID: 34736829.Majidova K, Handfield J, Kafi K, Martin RD, Kubinski R. Role of Digital Health and Artificial Intelligence in Inflammatory Bowel Disease: A Scoping Review. Genes (Basel). 2021 Sep 22;12(10):1465. doi: 10.3390/genes12101465. PMID: 34680860; PMCID: PMC8535572.Davis SP, Ross MSH, Adatorwovor R, Wei H. Telehealth and mobile health interventions in adults with inflammatory bowel disease: A mixed-methods systematic review. Res Nurs Health. 2021 Feb;44(1):155-172. doi: 10.1002/nur.22091. Epub 2020 Dec 11. PMID: 33305826.Yin AL, Hachuel D, Pollak JP, Scherl EJ, Estrin D. Digital Health Apps in the Clinical Care of Inflammatory Bowel Disease: Scoping Review. J Med Internet Res. 2019 Aug 19;21(8):e14630. doi: 10.2196/14630. PMID: 31429410; PMCID: PMC6718080.Jackson BD, Gray K, Knowles SR, De Cruz P. EHealth Technologies in Inflammatory Bowel Disease: A Systematic Review. J Crohns Colitis. 2016 Sep;10(9):1103-21. doi: 10.1093/ecco-jcc/jjw059. Epub 2016 Feb 29. PMID: 26928960.Aguas Peris M, Del Hoyo J, Bebia P, Faubel R, Barrios A, Bastida G, Valdivieso B, Nos P. Telemedicine in inflammatory bowel disease: opportunities and approaches. Inflamm Bowel Dis. 2015 Feb;21(2):392-9. doi: 10.1097/MIB.0000000000000241. PMID: 25437818.Huang VW, Reich KM, Fedorak RN. Distance management of inflammatory bowel disease: systematic review and meta-analysis. World J Gastroenterol. 2014 Jan 21;20(3):829-42. doi: 10.3748/wjg.v20.i3.829. PMID: 24574756; PMCID: PMC3921492.Knowles SR, Mikocka-Walus A. Utilization and efficacy of internet-based eHealth technology in gastroenterology: a systematic review. Scand J Gastroenterol. 2014 Apr;49(4):387-408. doi: 10.3109/00365521.2013.865259. Epub 2014 Feb 5. PMID: 24494974. | 3 healthcare professionals  | Oral and gastrointestinal |
| 42Question not discussed or ranked at workshop | How can digital technology improve communication between adolescents/ young people with IBD and their doctors? | Adolescents and young people with IBD require regular monitoring and assessment from clinicians in order to optimise long term outcomes. Digital technology will have an impact on how clinicians interact with patients with an evolution of the traditional face-to-face interaction with increasing digital workflows. Questions from stakeholders related to whether digital technology could increase accessibility and communication directly with doctors.*‘’Can there be an online doctor for 24/7 urgent questions.’’**‘’Would the communication be direct to the specialist doctor? Is there any plans to do this?’’**‘’Online doctors specific in IBD ‘’**‘Could apps be used by a patient to report directly to their doctors?’’**‘’Will reporting symptoms in an app be seen by a specialist?’’**‘’How apps can help communicate with doctors quickly?’’**‘’Interaction with main consultants/video calls’’* | Available evidence that partially answered the summary question:Gohil S, Majd Z, Sheneman JC, Abughosh SM. Interventions to improve medication adherence in inflammatory bowel disease: A systematic review. Patient Educ Couns. 2022 Jul;105(7):1731-1742. doi: 10.1016/j.pec.2021.10.017. Epub 2021 Oct 15. PMID: 34736829.Pang L, Liu H, Liu Z, Tan J, Zhou LY, Qiu Y, Lin X, He J, Li X, Lin S, Ghosh S, Mao R, Chen M. 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| 43Question not discussed or ranked at workshop | Will digital technology make it easier for adolescents/ young people with IBD to contact their IBD team and which types are best? | Adolescents and young people with IBD need easily accessible and flexible care to allow them to be monitored and treated without interruption to their education and minimising the need for hospital visits. Common questions from stakeholders relate to methods and types of digital technology which could facilitate remote interaction and communication with their IBD team.*‘’I’d like a better way to communicate with my IBD team rather than email or leaving a message’’**‘’I want to find a way to be able to have better communications to get help or appointments like at the IBD clinic, since it's difficult to reach a member of IBD team for help’’**‘’App to contact gastro team rather than emails’’**Question/chat with IBD nurse - does not need to always be ‘my’ IBD nurse could be centralised/general enquiry**‘’Instant messaging portals and video consultations that link you to healthcare teams’’**‘’Instant messaging with IBD team’’**‘’Can my daughter connect directly with her IBD team through an app?‘’**‘’Is it possible to email your IBD team?’’**‘’Would the apps be directly linked to the IBD team? Or would the patient just show it at their appointment?’’**‘’Is there a way we can have instant messaging with consultants or nurse specialists?*  *‘’How can digital technology make it easier to manage interactions with health care professionals?’’* *‘’Digital technology that would allow easy contact with an IBD team or consultant would be really helpful.’’**‘’Is there a way we can communicate with the IBD team that doesn't involve leaving answerphone messages? Email, text - something similar?’’**‘’It would be good if you could email the IBD nurses as I likely miss their call with work.’’**‘’Is there a way that people with IBD can use tech to contact their local IBD team without having to call?’’**‘’Instant messaging to IBD team and video connects’’**‘’Could a parent also communicate with their child/adolescent’s IBD team digitally?’’**‘’I'd like to use tech to contact healthcare more easily, perhaps support messaging services?’’**‘’It’s really hard to speak to anyone at my son’s hospital. A direct messaging service or place to leave a message requesting a call back/email would be helpful’’**‘’Can we use digital technology as an IBD helpline instead of using phone/email?’’* | Available evidence that partially answered the summary question:Majidova K, Handfield J, Kafi K, Martin RD, Kubinski R. Role of Digital Health and Artificial Intelligence in Inflammatory Bowel Disease: A Scoping Review. 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| 44Question not discussed or ranked at workshop | How can digital technology make it easier for adolescents/ young people with IBD to get their prescriptions and medications from the pharmacy or homecare company? | Digitalisation of prescription and distribution of medicine has enhanced the work of community and hospital pharmacists resulting in improved safety and patient care. Dispensing immunosuppressants and advanced therapies started in secondary care requires multiple steps and often leads to delays. Several adolescents and young people with IBD asked therapy specific questions including access to care, test result coordination, speciality pharmacy triage and distribution solutions.*‘’It would be good to be able to email the consultants secretary as twice now the consultant said they’d send a prescription and it’s not happened so I give up. I’m not on any medication as a result.’’**‘’It would be helpful to have an app/system that patients can use when running out of medications/prescriptions, that would automatically inform the IBD nurse specialist/ IBD team and the GP so they can proactively provide more supply.’’**‘’Can this help medication delivery? I take Imraldi and rely on a company who have on three occasions been responsible for missed doses of medication and are also difficult to contact. Unfortunately I have no choice over who delivers the medication.’’**‘’It is always so hard to get a prescription for Humira’’**‘’Medication reminders on when to take and when to order more.’’**‘’Smart Sharps bin to improve adherence and monitor subcutaneous biologics.’’**‘’Have pre-set time points for monitoring bloods when on immunosuppressive.’’* | Available evidence that partially answered the summary question:Nguyen NH, Martinez I, Atreja A, Sitapati AM, Sandborn WJ, Ohno-Machado L, Singh S. Digital Health Technologies for Remote Monitoring and Management of Inflammatory Bowel Disease: A Systematic Review. Am J Gastroenterol. 2022 Jan 1;117(1):78-97. doi: 10.14309/ajg.0000000000001545. PMID: 34751673; PMCID: PMC8987011.Gohil S, Majd Z, Sheneman JC, Abughosh SM. Interventions to improve medication adherence in inflammatory bowel disease: A systematic review. Patient Educ Couns. 2022 Jul;105(7):1731-1742. doi: 10.1016/j.pec.2021.10.017. Epub 2021 Oct 15. PMID: 34736829.Pang L, Liu H, Liu Z, Tan J, Zhou LY, Qiu Y, Lin X, He J, Li X, Lin S, Ghosh S, Mao R, Chen M. Role of Telemedicine in Inflammatory Bowel Disease: Systematic Review and Meta-analysis of Randomized Controlled Trials. J Med Internet Res. 2022 Mar 24;24(3):e28978. doi: 10.2196/28978. PMID: 35323120; PMCID: PMC8990345.Majidova K, Handfield J, Kafi K, Martin RD, Kubinski R. Role of Digital Health and Artificial Intelligence in Inflammatory Bowel Disease: A Scoping Review. Genes (Basel). 2021 Sep 22;12(10):1465. doi: 10.3390/genes12101465. PMID: 34680860; PMCID: PMC8535572.Davis SP, Ross MSH, Adatorwovor R, Wei H. Telehealth and mobile health interventions in adults with inflammatory bowel disease: A mixed-methods systematic review. Res Nurs Health. 2021 Feb;44(1):155-172. doi: 10.1002/nur.22091. Epub 2020 Dec 11. PMID: 33305826.Gordon M, Sinopoulou V, Akobeng AK, Lakunina S, Gjuladin-Hellon T, Bracewell K. Remote care through telehealth for people with inflammatory bowel disease. Cochrane Database Syst Rev. 2021 Apr 15;2021(4):CD014821. doi: 10.1002/14651858.CD014821. PMCID: PMC8078277.Yin AL, Hachuel D, Pollak JP, Scherl EJ, Estrin D. Digital Health Apps in the Clinical Care of Inflammatory Bowel Disease: Scoping Review. J Med Internet Res. 2019 Aug 19;21(8):e14630. doi: 10.2196/14630. PMID: 31429410; PMCID: PMC6718080.Kelso M, Feagins LA. Can Smartphones Help Deliver Smarter Care for Patients With Inflammatory Bowel Disease? Inflamm Bowel Dis. 2018 Jun 8;24(7):1453-1459. doi: 10.1093/ibd/izy162. PMID: 29868764. | 3 adolescent/ young people with IBD3 healthcare professionals1 parent/carer | Oral and gastrointestinal |
| 45Question not discussed or ranked at workshop  | Can digital technology make it easier for adolescents/ young people with IBD to let their parents/carers know about how they feel rather than telling them face-to-face? | Family and carers have a huge impact on the personal development of a young person. Adolescents and young people with IBD may have different attitudes towards disease and communication styles compared to adults. This questions relates to how digital technology can facilitate open communication between patients and their parents or carers.*‘’Could there be apps that can link family members so you can tell them you are suffering without having to say in person.’’* | None identified | 1 adolescent/ young person with IBD | Oral and gastrointestinal |