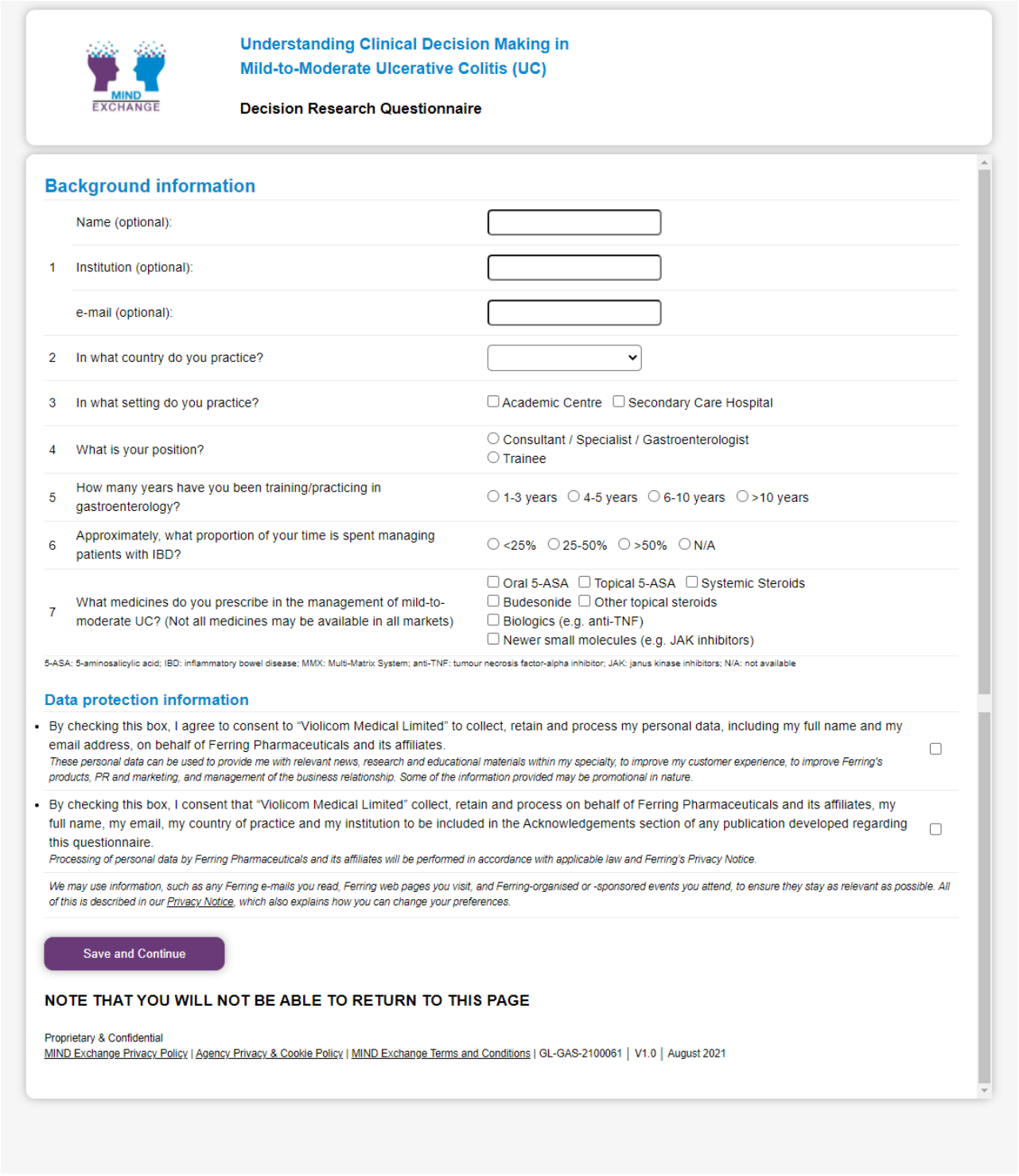
Supplementary File 1. Understanding clinical decision-making in mild-to-moderate ulcerative colitis: decision research questionnaire.



MIND EXCHANGE

Understanding Clinical Decision Making in Mild-to-Moderate Ulcerative Colitis (UC)

Decision Research Questionnaire

Background information

	Name (optional):	
1	Institution (optional):	
	e-mail (optional):	
2	In what country do you practice?	
3	In what setting do you practice?	☐ Academic Centre ☐ Secondary Care Hospital
4	What is your position?	○ Consultant / Specialist / Gastroenterologist ○ Trainee
5	How many years have you been training/practicing in gastroenterology?	○ 1-3 years ○ 4-5 years ○ 6-10 years ○ >10 years
6	Approximately, what proportion of your time is spent managing patients with IBD?	○ <25% ○ 25-50% ○ >50% ○ N/A
7	What medicines do you prescribe in the management of mild-to-moderate UC? (Not all medicines may be available in all markets)	☐ Oral 5-ASA ☐ Topical 5-ASA ☐ Systemic Steroids ☐ Budesonide ☐ Other topical steroids ☐ Biologics (e.g. anti-TNF) ☐ Newer small molecules (e.g. JAK inhibitors)

5-ASA: 5-aminosalicylic acid; IBD: inflammatory bowel disease; MMX: Multi-Matrix System; anti-TNF: tumour necrosis factor-alpha inhibitor; JAK: janus kinase inhibitors; N/A: not available

Data protection information

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Understanding Clinical Decision Making in Mild-to-Moderate Ulcerative Colitis (UC)

Decision Research Questionnaire

Instructions

There are three sections or parts to the remainder of the questionnaire:

- Section 1 – covering the management of patients with active mild-to-moderate UC
- Section 2 – covering the management of patients in remission following a mild-to-moderate UC flare
- Section 3 – covering patient self-management in mild-to-moderate UC

For each section, please score each Catalogue item by making a vertical mark on the line (visual analogue scale) next to the item to indicate how important you think that particular item is in the management of patients with mild-to-moderate UC.

For example:

Availability of imaging modality

- very unimportant_____I_____very important □ Not relevant

Patients' reluctance to use rectal therapy

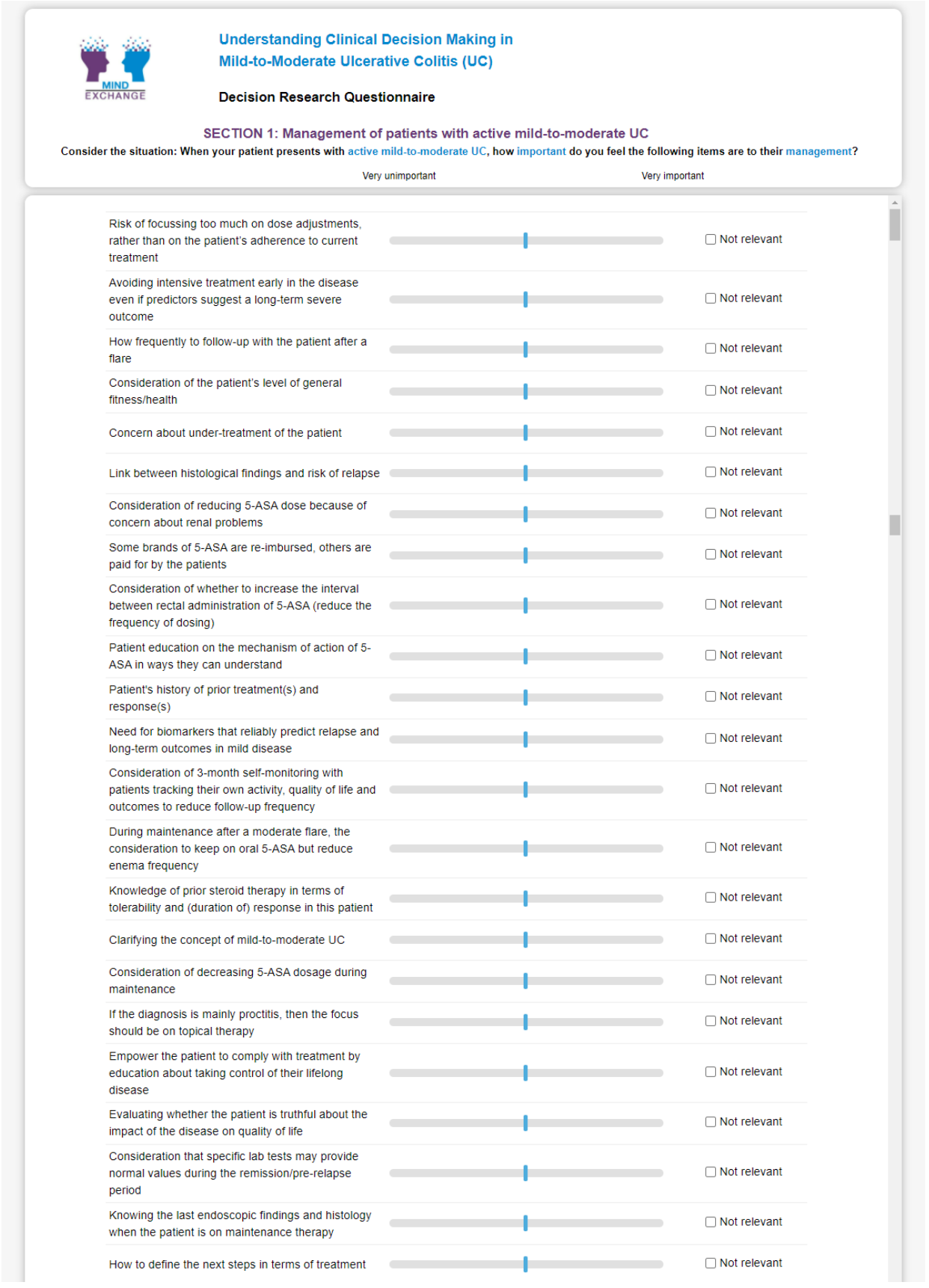
- very unimportant_____I_____very important □ Not relevant

Please note that:

- The Catalogue contains 158 items with the wording adapted from the MIND Exchange Steering Committee – sometimes the items will be quite specific and other times more general
- In each section, the Catalogue items are repeated – this will enable multivariate analysis on the relative importance of and interrelationships between the items within each clinical context (flare, remission and patient self-management)
- The Catalogue items are randomised – this reduces any (unintentional) rationalisation of answers and reduces fatigue
- There is the option of marking an item as 'Not relevant' if not applicable to clinical practice in your country or your own practice
- This questionnaire should take 30-45 minutes to complete
- The statements herein are provided solely for market research purposes
- Availability of treatment options may vary by market. If a question relates to a treatment option not available in your market, please indicate "Not relevant"

Please do not spend too much time thinking about each item – your immediate reaction is what we are after!

Continue



Understanding Clinical Decision Making in Mild-to-Moderate Ulcerative Colitis (UC)

Decision Research Questionnaire

SECTION 1: Management of patients with active mild-to-moderate UC

Consider the situation: When your patient presents with active mild-to-moderate UC, how important do you feel the following items are to their management?

	Very unimportant — Very important	
Risk of focussing too much on dose adjustments, rather than on the patient's adherence to current treatment		☐ Not relevant
Avoiding intensive treatment early in the disease even if predictors suggest a long-term severe outcome		☐ Not relevant
How frequently to follow-up with the patient after a flare		☐ Not relevant
Consideration of the patient's level of general fitness/health		☐ Not relevant
Concern about under-treatment of the patient		☐ Not relevant
Link between histological findings and risk of relapse		☐ Not relevant
Consideration of reducing 5-ASA dose because of concern about renal problems		☐ Not relevant
Some brands of 5-ASA are re-imbursed, others are paid for by the patients		☐ Not relevant
Consideration of whether to increase the interval between rectal administration of 5-ASA (reduce the frequency of dosing)		☐ Not relevant
Patient education on the mechanism of action of 5-ASA in ways they can understand		☐ Not relevant
Patient's history of prior treatment(s) and response(s)		☐ Not relevant
Need for biomarkers that reliably predict relapse and long-term outcomes in mild disease		☐ Not relevant
Consideration of 3-month self-monitoring with patients tracking their own activity, quality of life and outcomes to reduce follow-up frequency		☐ Not relevant
During maintenance after a moderate flare, the consideration to keep on oral 5-ASA but reduce enema frequency		☐ Not relevant
Knowledge of prior steroid therapy in terms of tolerability and (duration of) response in this patient		☐ Not relevant
Clarifying the concept of mild-to-moderate UC		☐ Not relevant
Consideration of decreasing 5-ASA dosage during maintenance		☐ Not relevant
If the diagnosis is mainly proctitis, then the focus should be on topical therapy		☐ Not relevant
Empower the patient to comply with treatment by education about taking control of their lifelong disease		☐ Not relevant
Evaluating whether the patient is truthful about the impact of the disease on quality of life		☐ Not relevant
Consideration that specific lab tests may provide normal values during the remission/pre-relapse period		☐ Not relevant
Knowing the last endoscopic findings and histology when the patient is on maintenance therapy		☐ Not relevant
How to define the next steps in terms of treatment		☐ Not relevant

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Providing the patient with a list of factors to reduce the risk of relapse such as diet, physical activity, rest and so on	☐ Not relevant
Likelihood of patient acceptance of sigmoidoscopy	☐ Not relevant
Consideration of what the diagnosis of UC means to this patient	☐ Not relevant
Consideration of the use of sigmoidoscopy to confirm the patient is in remission	☐ Not relevant
Whether functional symptoms remain after the flare and advising the patient on treating them	☐ Not relevant
Consideration of moving to a biologic	☐ Not relevant
Challenges in diagnosing mild UC	☐ Not relevant
Reduce induction dose by half for continued maintenance dose	☐ Not relevant
Consideration of not reducing the dose of 5-ASA if patients are satisfied with their treatment	☐ Not relevant
Communicating with the patient and fully discussing the therapeutic options	☐ Not relevant
Psychological and nutritional support for patients ensuring they know the physician is by their side for symptoms/worries	☐ Not relevant
Informing the patient about different treatment options in case of relapse	☐ Not relevant
Re-assuring the patients who may be worried or anxious or feel stigmatised about a diagnosis of UC	☐ Not relevant
Consideration that patient focus on functional symptoms post-flare may lead them to consider that treatment is not working	☐ Not relevant
Courses involving psychologists, dieticians, nutritionists helpful in sharing ideas from other fields of expertise with patients	☐ Not relevant
Stratification of patient in terms of risk of progression	☐ Not relevant
Whether the patient experienced a flare on optimised therapy	☐ Not relevant
Consideration of the severity of disease at initial diagnosis	☐ Not relevant
Lack of consistent evidence about a diet that is better for UC patients	☐ Not relevant
Sufficiency of endoscopically identified erythema as a guide for treatment	☐ Not relevant
Use of histological remission as an indicator for 5-ASA management	☐ Not relevant
Consideration of switching to other drugs from 5-ASA	☐ Not relevant
Evaluation of whether previous diagnosis of mild disease has been carried out correctly	☐ Not relevant
Evaluation of co-morbidities	☐ Not relevant
Consideration of discontinuing 5-ASA if mucosal healing is achieved with biologic	☐ Not relevant
Whether another doctor has already tried to treat the patient	☐ Not relevant
If second or third flare, reassessment of the extent of disease	☐ Not relevant
Concern about over-treatment of the patient	☐ Not relevant
The thought that short term steroid treatment is generally well-tolerated	☐ Not relevant
Education of surgeons about medical treatment of mild disease	☐ Not relevant

Training patients and their General Practitioners (GPs) on how to manage care over the long-term		☐ Not relevant
Let patients know that your interests align with their interests, and they should continue to comply with medical recommendations		☐ Not relevant
Avoiding corticosteroids in a first flare		☐ Not relevant
Managing mild disease during the period in which it occurs		☐ Not relevant
Use of faecal calprotectin as a means of avoiding sigmoidoscopy		☐ Not relevant
Use of faecal calprotectin to monitor disease activity		☐ Not relevant
Close monitoring of disease activity using Nucleosome Assembly Proteins		☐ Not relevant
Consideration of good quality of life as the ultimate goal		☐ Not relevant
Optimising 5-ASA dose post flare to avoid future relapses		☐ Not relevant
Maintenance of high dose 5-ASA until it is no longer effective		☐ Not relevant
Consideration of non-steroidal anti-inflammatory drugs (NSAIDs) as a potential exacerbating factor		☐ Not relevant
Education of patients on importance of biomarkers in monitoring their disease post-flare		☐ Not relevant
Education of the patient that adherence to treatment contributes to staying in remission		☐ Not relevant
Measurement of the baseline level of faecal calprotectin		☐ Not relevant
Consideration of the history of disease before relapse		☐ Not relevant
Evaluation of patient reported outcomes		☐ Not relevant
Consideration of increasing rectal 5-ASA frequency		☐ Not relevant
Consideration of reducing the burden on health care system		☐ Not relevant
Consideration of whether treatment with 5-ASA will be enough		☐ Not relevant
Keeping patients on 5-ASA even while on biologic if they have a higher risk of colorectal cancer		☐ Not relevant
Consideration of the duration of remission before a flare		☐ Not relevant
Consideration of antibiotics as a potential exacerbating factor		☐ Not relevant
Engaging the patient in their management through education and understanding their disease		☐ Not relevant
Establishing contingency plans with the patient in case of relapse		☐ Not relevant
Consideration of the use of sigmoidoscopy to screen for dysplasia or colorectal cancer		☐ Not relevant
Taking account of limited data from Cochrane meta-analysis supporting high doses of 5-ASA		☐ Not relevant
Consideration of the patient's age		☐ Not relevant
Potential patient reticence to take azathioprine because of the risks of adverse effects		☐ Not relevant
Keeping on 5-ASA for maintenance		☐ Not relevant
Involving the nurse to help to inform the patient about red flags amongst symptoms and signs to be communicated immediately		☐ Not relevant
Discussion of other treatment options including dose optimisation if the patient is complaining		☐ Not relevant

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Use of histological remission as a marker for lower risk of relapse		☐ Not relevant
Consideration of how to improve maintenance strategy by increasing dose		☐ Not relevant
Empowerment allowing for patients' differing points of view, perceptions, knowledge and abilities		☐ Not relevant
Confirm the flare is inflammatory disease not irritable bowel syndrome (IBS)-like symptoms		☐ Not relevant
The use of maintenance periods as a patient educational opportunity to cover future patterns, treatment options, surveillance and family risk		☐ Not relevant
Consideration that side-effects of 5-ASA may be more idiosyncratic than dose-related		☐ Not relevant
Perception that the milder the flare the more difficult the treatment decision		☐ Not relevant
Consideration of whether sigmoidoscopy is a priority and should be performed or not		☐ Not relevant
Consideration of hidden super-infections as a potential exacerbating factor		☐ Not relevant
After a second or third course of steroids whether 5-ASA may not be maintaining the patient well enough		☐ Not relevant
Whether the patient is on any other type of treatment for IBD		☐ Not relevant
Evaluate disease activity e.g. frequency of bowel movement, blood in stool, abdominal pain to guide treatment choices		☐ Not relevant
Relative effectiveness of generic 5-ASA versus commercial products		☐ Not relevant
Potentially reducing dose of 5-ASA because of cost of therapy		☐ Not relevant
Regularly monitor for blood in stool		☐ Not relevant
Whether the patient has more than 2 relapses within a year		☐ Not relevant
Understanding how the previous flare was treated		☐ Not relevant
Consideration of whether steroids were used to treat the last flare and for how long		☐ Not relevant
Regular use of faecal calprotectin to confirm remission		☐ Not relevant
Consideration that a mild flare might just require an increased dose of 5-ASA		☐ Not relevant
Consideration of stress as a potential exacerbating factor		☐ Not relevant
Challenges in persuading the patient to use rectal therapy, especially if disease is confined to the rectum		☐ Not relevant
Consideration of how to improve maintenance strategy by adding or changing therapy		☐ Not relevant
Faecal calprotectin may not distinguish between infection and inflammation		☐ Not relevant
Challenges in considering empowerment with some patients		☐ Not relevant
Educating patients on increasing rectal therapy when there is blood in the stool		☐ Not relevant
The current difficulty of predicting a good trajectory for newly diagnosed patients		☐ Not relevant
Consideration of increasing the dose of oral 5-ASA		☐ Not relevant
Evaluation of extra-intestinal manifestations e.g. skin, joints		☐ Not relevant
Ensuring that the patient is still in full remission		☐ Not relevant

Consideration that a mild flare involving the rectum might just require the addition of suppositories		☐ Not relevant
Recent reviews showing benefit of higher 5-ASA doses for maintenance		☐ Not relevant
Assessing the severity of a flare		☐ Not relevant
Consideration of the patient's priorities		☐ Not relevant
Stratifying newly diagnosed patients on the basis of risk factors of progression		☐ Not relevant
Checking compliance especially with rectal treatment		☐ Not relevant
Evaluation of endoscopic findings to determine presence of deep ulceration and extent of disease		☐ Not relevant
Regular evaluation of the blood count		☐ Not relevant
Consideration of lack of sleep as a potential exacerbating factor		☐ Not relevant
Regular evaluation of C-reactive protein		☐ Not relevant
Stratifying newly diagnosed patients on the basis of response to therapy		☐ Not relevant
Understand how treatment remission was achieved previously		☐ Not relevant
Not regarding histological remission as the primary treatment target		☐ Not relevant
Accounting for risks of skin cancer and cervical dysplasia if maintenance is achieved with anti-TNF		☐ Not relevant
Potentially raising patients' expectations from therapy and setting higher goals		☐ Not relevant
Regularly monitoring of body weight and general health		☐ Not relevant
Potential for patients to stop taking medication when they are doing well		☐ Not relevant
Educating the patient on when to seek hospital help or simply communicate with nurses or physicians		☐ Not relevant
Lack of indication for azathioprine or biologics when remission has been of long duration		☐ Not relevant
Consideration of non-flare-related gastro-enteritis as a potential exacerbating factor		☐ Not relevant
Use of faecal calprotectin level as a biomarker for risk of relapse		☐ Not relevant
Not going back to 5-ASA dose at which a flare occurred after remission unless the pattern of disease has changed		☐ Not relevant
Empowerment might include patient control of dose, route or frequency of 5-ASA		☐ Not relevant
Consideration of whether remission diagnosis was based on clinical symptoms		☐ Not relevant
Use of faecal calprotectin to help optimise 5-ASA therapy		☐ Not relevant
Usefulness of "top and tail' (oral and rectal) therapy for proctitis and distal colitis		☐ Not relevant
Consideration of the treatment used for management at initial diagnosis		☐ Not relevant
Consideration of reduction in relapse by 50% as a therapy goal (rather than relapse free)		☐ Not relevant
Consideration that relapse every 5 to 10 years means 5-ASA is effective		☐ Not relevant
Spending time with patients to educate them about their disease		☐ Not relevant

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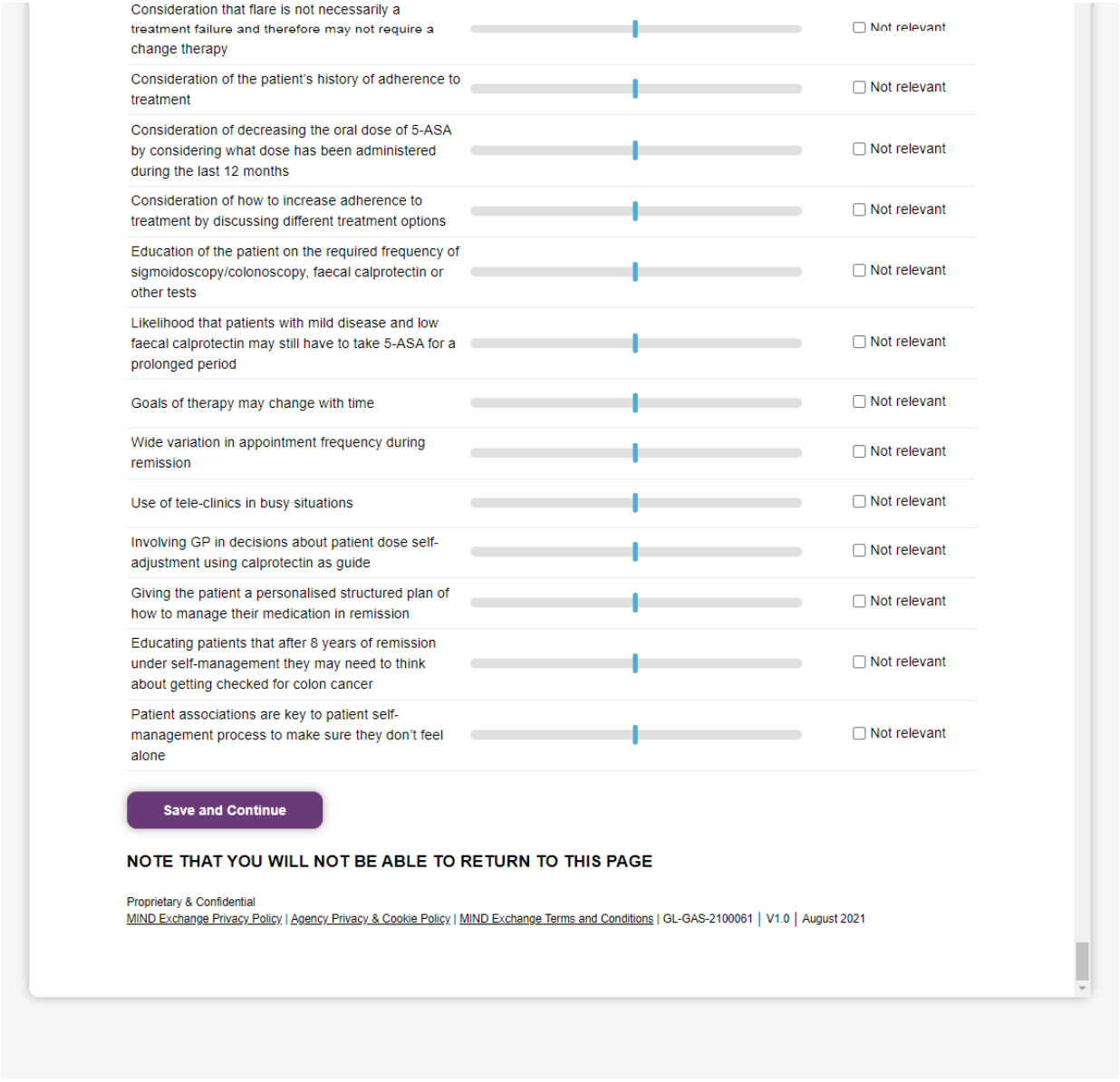

Consideration that flare is not necessarily a treatment failure and therefore may not require a change therapy		☐ Not relevant
Consideration of the patient's history of adherence to treatment		☐ Not relevant
Consideration of decreasing the oral dose of 5-ASA by considering what dose has been administered during the last 12 months		☐ Not relevant
Consideration of how to increase adherence to treatment by discussing different treatment options		☐ Not relevant
Education of the patient on the required frequency of sigmoidoscopy/colonoscopy, faecal calprotectin or other tests		☐ Not relevant
Likelihood that patients with mild disease and low faecal calprotectin may still have to take 5-ASA for a prolonged period		☐ Not relevant
Goals of therapy may change with time		☐ Not relevant
Wide variation in appointment frequency during remission		☐ Not relevant
Use of tele-clinics in busy situations		☐ Not relevant
Involving GP in decisions about patient dose self-adjustment using calprotectin as guide		☐ Not relevant
Giving the patient a personalised structured plan of how to manage their medication in remission		☐ Not relevant
Educating patients that after 8 years of remission under self-management they may need to think about getting checked for colon cancer		☐ Not relevant
Patient associations are key to patient self-management process to make sure they don't feel alone		☐ Not relevant

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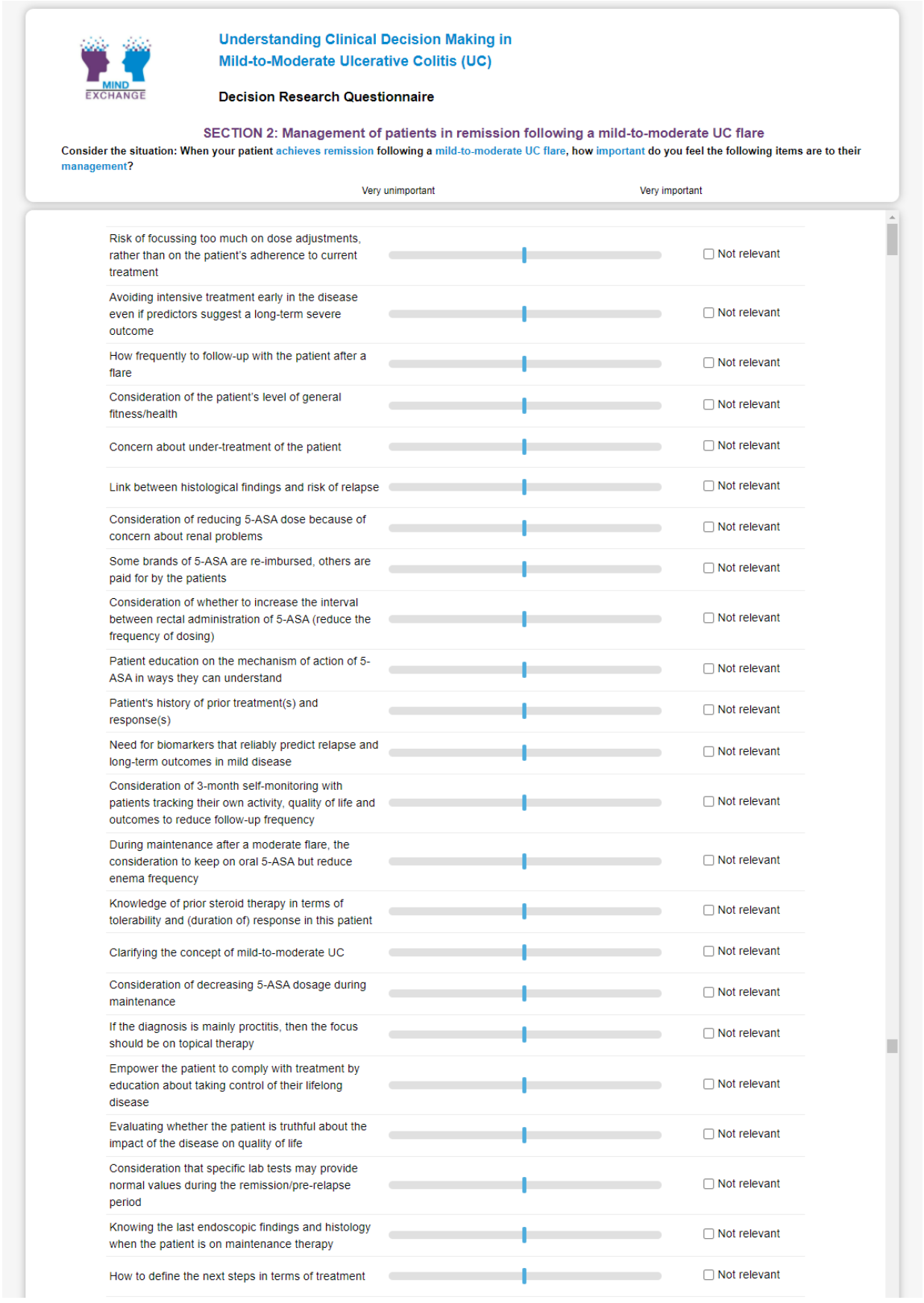

Understanding Clinical Decision Making in Mild-to-Moderate Ulcerative Colitis (UC)

Decision Research Questionnaire

SECTION 2: Management of patients in remission following a mild-to-moderate UC flare

Consider the situation: When your patient achieves remission following a mild-to-moderate UC flare, how important do you feel the following items are to their management?

	Very unimportant — Very important	
Risk of focussing too much on dose adjustments, rather than on the patient's adherence to current treatment		☐ Not relevant
Avoiding intensive treatment early in the disease even if predictors suggest a long-term severe outcome		☐ Not relevant
How frequently to follow-up with the patient after a flare		☐ Not relevant
Consideration of the patient's level of general fitness/health		☐ Not relevant
Concern about under-treatment of the patient		☐ Not relevant
Link between histological findings and risk of relapse		☐ Not relevant
Consideration of reducing 5-ASA dose because of concern about renal problems		☐ Not relevant
Some brands of 5-ASA are re-imbursed, others are paid for by the patients		☐ Not relevant
Consideration of whether to increase the interval between rectal administration of 5-ASA (reduce the frequency of dosing)		☐ Not relevant
Patient education on the mechanism of action of 5-ASA in ways they can understand		☐ Not relevant
Patient's history of prior treatment(s) and response(s)		☐ Not relevant
Need for biomarkers that reliably predict relapse and long-term outcomes in mild disease		☐ Not relevant
Consideration of 3-month self-monitoring with patients tracking their own activity, quality of life and outcomes to reduce follow-up frequency		☐ Not relevant
During maintenance after a moderate flare, the consideration to keep on oral 5-ASA but reduce enema frequency		☐ Not relevant
Knowledge of prior steroid therapy in terms of tolerability and (duration of) response in this patient		☐ Not relevant
Clarifying the concept of mild-to-moderate UC		☐ Not relevant
Consideration of decreasing 5-ASA dosage during maintenance		☐ Not relevant
If the diagnosis is mainly proctitis, then the focus should be on topical therapy		☐ Not relevant
Empower the patient to comply with treatment by education about taking control of their lifelong disease		☐ Not relevant
Evaluating whether the patient is truthful about the impact of the disease on quality of life		☐ Not relevant
Consideration that specific lab tests may provide normal values during the remission/pre-relapse period		☐ Not relevant
Knowing the last endoscopic findings and histology when the patient is on maintenance therapy		☐ Not relevant
How to define the next steps in terms of treatment		☐ Not relevant

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Providing the patient with a list of factors to reduce the risk of relapse such as diet, physical activity, rest and so on		☐ Not relevant
Likelihood of patient acceptance of sigmoidoscopy		☐ Not relevant
Consideration of what the diagnosis of UC means to this patient		☐ Not relevant
Consideration of the use of sigmoidoscopy to confirm the patient is in remission		☐ Not relevant
Whether functional symptoms remain after the flare and advising the patient on treating them		☐ Not relevant
Consideration of moving to a biologic		☐ Not relevant
Challenges in diagnosing mild UC		☐ Not relevant
Reduce induction dose by half for continued maintenance dose		☐ Not relevant
Consideration of not reducing the dose of 5-ASA if patients are satisfied with their treatment		☐ Not relevant
Communicating with the patient and fully discussing the therapeutic options		☐ Not relevant
Psychological and nutritional support for patients ensuring they know the physician is by their side for symptoms/worries		☐ Not relevant
Informing the patient about different treatment options in case of relapse		☐ Not relevant
Re-assuring the patients who may be worried or anxious or feel stigmatised about a diagnosis of UC		☐ Not relevant
Consideration that patient focus on functional symptoms post-flare may lead them to consider that treatment is not working		☐ Not relevant
Courses involving psychologists, dieticians, nutritionists helpful in sharing ideas from other fields of expertise with patients		☐ Not relevant
Stratification of patient in terms of risk of progression		☐ Not relevant
Whether the patient experienced a flare on optimised therapy		☐ Not relevant
Consideration of the severity of disease at initial diagnosis		☐ Not relevant
Lack of consistent evidence about a diet that is better for UC patients		☐ Not relevant
Sufficiency of endoscopically identified erythema as a guide for treatment		☐ Not relevant
Use of histological remission as an indicator for 5-ASA management		☐ Not relevant
Consideration of switching to other drugs from 5-ASA		☐ Not relevant
Evaluation of whether previous diagnosis of mild disease has been carried out correctly		☐ Not relevant
Evaluation of co-morbidities		☐ Not relevant
Consideration of discontinuing 5-ASA if mucosal healing is achieved with biologic		☐ Not relevant
Whether another doctor has already tried to treat the patient		☐ Not relevant
If second or third flare, reassessment of the extent of disease		☐ Not relevant
Concern about over-treatment of the patient		☐ Not relevant
The thought that short term steroid treatment is generally well-tolerated		☐ Not relevant
Education of surgeons about medical treatment of mild disease		☐ Not relevant

Training patients and their General Practitioners (GPs) on how to manage care over the long-term		☐ Not relevant
Let patients know that your interests align with their interests, and they should continue to comply with medical recommendations		☐ Not relevant
Avoiding corticosteroids in a first flare		☐ Not relevant
Managing mild disease during the period in which it occurs		☐ Not relevant
Use of faecal calprotectin as a means of avoiding sigmoidoscopy		☐ Not relevant
Use of faecal calprotectin to monitor disease activity		☐ Not relevant
Close monitoring of disease activity using Nucleosome Assembly Proteins		☐ Not relevant
Consideration of good quality of life as the ultimate goal		☐ Not relevant
Optimising 5-ASA dose post flare to avoid future relapses		☐ Not relevant
Maintenance of high dose 5-ASA until it is no longer effective		☐ Not relevant
Consideration of non-steroidal anti-inflammatory drugs (NSAIDs) as a potential exacerbating factor		☐ Not relevant
Education of patients on importance of biomarkers in monitoring their disease post-flare		☐ Not relevant
Education of the patient that adherence to treatment contributes to staying in remission		☐ Not relevant
Measurement of the baseline level of faecal calprotectin		☐ Not relevant
Consideration of the history of disease before relapse		☐ Not relevant
Evaluation of patient reported outcomes		☐ Not relevant
Consideration of increasing rectal 5-ASA frequency		☐ Not relevant
Consideration of reducing the burden on health care system		☐ Not relevant
Consideration of whether treatment with 5-ASA will be enough		☐ Not relevant
Keeping patients on 5-ASA even while on biologic if they have a higher risk of colorectal cancer		☐ Not relevant
Consideration of the duration of remission before a flare		☐ Not relevant
Consideration of antibiotics as a potential exacerbating factor		☐ Not relevant
Engaging the patient in their management through education and understanding their disease		☐ Not relevant
Establishing contingency plans with the patient in case of relapse		☐ Not relevant
Consideration of the use of sigmoidoscopy to screen for dysplasia or colorectal cancer		☐ Not relevant
Taking account of limited data from Cochrane meta-analysis supporting high doses of 5-ASA		☐ Not relevant
Consideration of the patient's age		☐ Not relevant
Potential patient reticence to take azathioprine because of the risks of adverse effects		☐ Not relevant
Keeping on 5-ASA for maintenance		☐ Not relevant
Involving the nurse to help to inform the patient about red flags amongst symptoms and signs to be communicated immediately		☐ Not relevant

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Discussion of other treatment options including dose optimisation if the patient is complaining		☐ Not relevant
Use of histological remission as a marker for lower risk of relapse		☐ Not relevant
Consideration of how to improve maintenance strategy by increasing dose		☐ Not relevant
Empowerment allowing for patients' differing points of view, perceptions, knowledge and abilities		☐ Not relevant
Confirm the flare is inflammatory disease not irritable bowel syndrome (IBS)-like symptoms		☐ Not relevant
The use of maintenance periods as a patient educational opportunity to cover future patterns, treatment options, surveillance and family risk		☐ Not relevant
Consideration that side-effects of 5-ASA may be more idiosyncratic than dose-related		☐ Not relevant
Perception that the milder the flare the more difficult the treatment decision		☐ Not relevant
Consideration of whether sigmoidoscopy is a priority and should be performed or not		☐ Not relevant
Consideration of hidden super-infections as a potential exacerbating factor		☐ Not relevant
After a second or third course of steroids whether 5-ASA may not be maintaining the patient well enough		☐ Not relevant
Whether the patient is on any other type of treatment for IBD		☐ Not relevant
Evaluate disease activity e.g. frequency of bowel movement, blood in stool, abdominal pain to guide treatment choices		☐ Not relevant
Relative effectiveness of generic 5-ASA versus commercial products		☐ Not relevant
therapy, especially if disease is confined to the rectum		☐ Not relevant
Consideration of how to improve maintenance strategy by adding or changing therapy		☐ Not relevant
Faecal calprotectin may not distinguish between infection and inflammation		☐ Not relevant
Challenges in considering empowerment with some patients		☐ Not relevant
Educating patients on increasing rectal therapy when there is blood in the stool		☐ Not relevant
The current difficulty of predicting a good trajectory for newly diagnosed patients		☐ Not relevant
Consideration of increasing the dose of oral 5-ASA		☐ Not relevant
Evaluation of extra-intestinal manifestations e.g. skin, joints		☐ Not relevant
Ensuring that the patient is still in full remission		☐ Not relevant
Consideration that a mild flare involving the rectum might just require the addition of suppositories		☐ Not relevant
Recent reviews showing benefit of higher 5-ASA doses for maintenance		☐ Not relevant
Assessing the severity of a flare		☐ Not relevant
Consideration of the patient's priorities		☐ Not relevant
Stratifying newly diagnosed patients on the basis of risk factors of progression		☐ Not relevant
Checking compliance especially with rectal treatment		☐ Not relevant
Evaluation of endoscopic findings to determine presence of deep ulceration and extent of disease		☐ Not relevant
Regular evaluation of the blood count		☐ Not relevant

Consideration of lack of sleep as a potential exacerbating factor		☐ Not relevant
Regular evaluation of C-reactive protein		☐ Not relevant
Stratifying newly diagnosed patients on the basis of response to therapy		☐ Not relevant
Understand how treatment remission was achieved previously		☐ Not relevant
Not regarding histological remission as the primary treatment target		☐ Not relevant
Accounting for risks of skin cancer and cervical dysplasia if maintenance is achieved with anti-TNF		☐ Not relevant
Potentially raising patients' expectations from therapy and setting higher goals		☐ Not relevant
Regularly monitoring of body weight and general health		☐ Not relevant
Potential for patients to stop taking medication when they are doing well		☐ Not relevant
Educating the patient on when to seek hospital help or simply communicate with nurses or physicians		☐ Not relevant
Lack of indication for azathioprine or biologics when remission has been of long duration		☐ Not relevant
Consideration of non-flare-related gastro-enteritis as a potential exacerbating factor		☐ Not relevant
Use of faecal calprotectin level as a biomarker for risk of relapse		☐ Not relevant
Not going back to 5-ASA dose at which a flare occurred after remission unless the pattern of disease has changed		☐ Not relevant
Empowerment might include patient control of dose, route or frequency of 5-ASA		☐ Not relevant
Consideration of whether remission diagnosis was based on clinical symptoms		☐ Not relevant
Use of faecal calprotectin to help optimise 5-ASA therapy		☐ Not relevant
Usefulness of "top and tail' (oral and rectal) therapy for proctitis and distal colitis		☐ Not relevant
Consideration of the treatment used for management at initial diagnosis		☐ Not relevant
Consideration of reduction in relapse by 50% as a therapy goal (rather than relapse free)		☐ Not relevant
Consideration that relapse every 5 to 10 years means 5-ASA is effective		☐ Not relevant
Spending time with patients to educate them about their disease		☐ Not relevant
Consideration that flare is not necessarily a treatment failure and therefore may not require a change therapy		☐ Not relevant
Consideration of the patient's history of adherence to treatment		☐ Not relevant
Consideration of decreasing the oral dose of 5-ASA by considering what dose has been administered during the last 12 months		☐ Not relevant
Consideration of how to increase adherence to treatment by discussing different treatment options		☐ Not relevant
Education of the patient on the required frequency of sigmoidoscopy/colonoscopy, faecal calprotectin or other tests		☐ Not relevant
Likelihood that patients with mild disease and low faecal calprotectin may still have to take 5-ASA for a prolonged period		☐ Not relevant
Goals of therapy may change with time		☐ Not relevant

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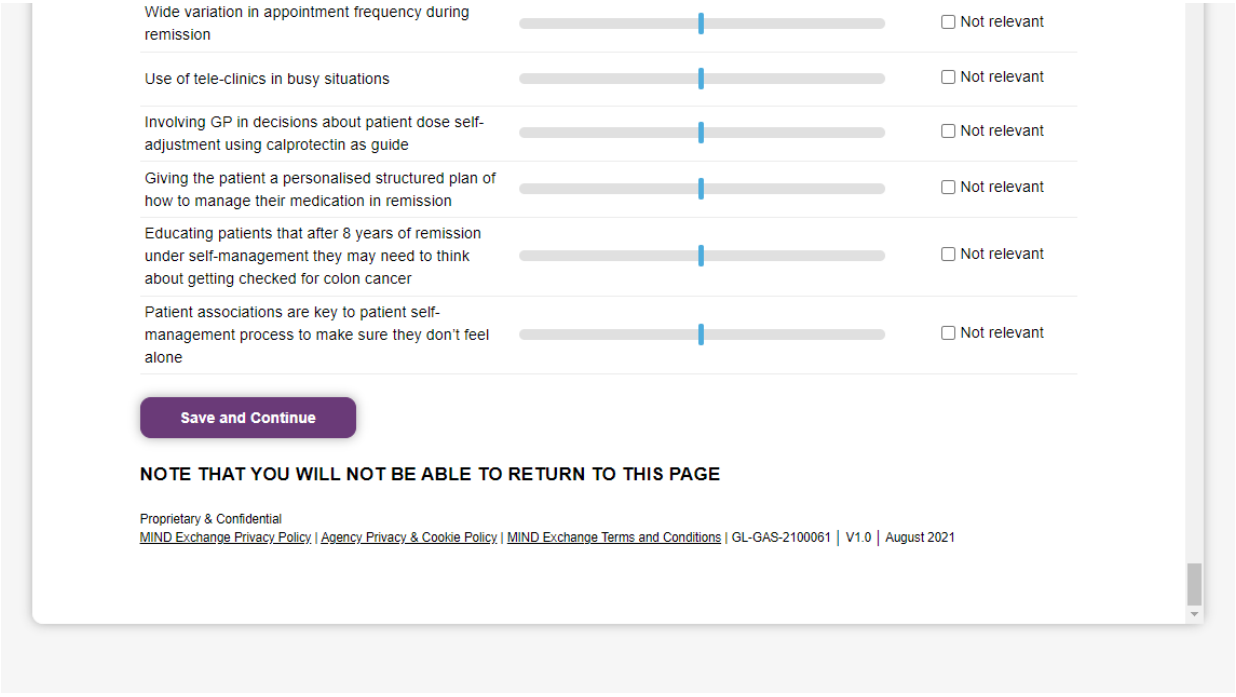

Understanding Clinical Decision Making in Mild-to-Moderate Ulcerative Colitis (UC)

Decision Research Questionnaire

SECTION 3: Patient self-management in mild-to-moderate UC

Consider the situation: Self-management and empowerment of patients with mild-to-moderate UC, how important do you feel the following items are to your patients' self-management of their UC?

	Very unimportant — Very important	
Risk of focussing too much on dose adjustments, rather than on the patient's adherence to current treatment		☐ Not relevant
Avoiding intensive treatment early in the disease even if predictors suggest a long-term severe outcome		☐ Not relevant
How frequently to follow-up with the patient after a flare		☐ Not relevant
Consideration of the patient's level of general fitness/health		☐ Not relevant
Concern about under-treatment of the patient		☐ Not relevant
Link between histological findings and risk of relapse		☐ Not relevant
Consideration of reducing 5-ASA dose because of concern about renal problems		☐ Not relevant
Some brands of 5-ASA are re-imbursed, others are paid for by the patients		☐ Not relevant
Consideration of whether to increase the interval between rectal administration of 5-ASA (reduce the frequency of dosing)		☐ Not relevant
Patient education on the mechanism of action of 5-ASA in ways they can understand		☐ Not relevant
Patient's history of prior treatment(s) and response(s)		☐ Not relevant
Need for biomarkers that reliably predict relapse and long-term outcomes in mild disease		☐ Not relevant
Consideration of 3-month self-monitoring with patients tracking their own activity, quality of life and outcomes to reduce follow-up frequency		☐ Not relevant
During maintenance after a moderate flare, the consideration to keep on oral 5-ASA but reduce enema frequency		☐ Not relevant
Knowledge of prior steroid therapy in terms of tolerability and (duration of) response in this patient		☐ Not relevant
Clarifying the concept of mild-to-moderate UC		☐ Not relevant
Consideration of decreasing 5-ASA dosage during maintenance		☐ Not relevant
If the diagnosis is mainly proctitis, then the focus should be on topical therapy		☐ Not relevant
Empower the patient to comply with treatment by education about taking control of their lifelong disease		☐ Not relevant
Evaluating whether the patient is truthful about the impact of the disease on quality of life		☐ Not relevant
Consideration that specific lab tests may provide normal values during the remission/pre-relapse period		☐ Not relevant
Knowing the last endoscopic findings and histology when the patient is on maintenance therapy		☐ Not relevant
How to define the next steps in terms of treatment		☐ Not relevant

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Providing the patient with a list of factors to reduce the risk of relapse such as diet, physical activity, rest and so on		☐ Not relevant
Likelihood of patient acceptance of sigmoidoscopy		☐ Not relevant
Consideration of what the diagnosis of UC means to this patient		☐ Not relevant
Consideration of the use of sigmoidoscopy to confirm the patient is in remission		☐ Not relevant
Whether functional symptoms remain after the flare and advising the patient on treating them		☐ Not relevant
Consideration of moving to a biologic		☐ Not relevant
Challenges in diagnosing mild UC		☐ Not relevant
Reduce induction dose by half for continued maintenance dose		☐ Not relevant
Consideration of not reducing the dose of 5-ASA if patients are satisfied with their treatment		☐ Not relevant
Communicating with the patient and fully discussing the therapeutic options		☐ Not relevant
Psychological and nutritional support for patients ensuring they know the physician is by their side for symptoms/worries		☐ Not relevant
Informing the patient about different treatment options in case of relapse		☐ Not relevant
Re-assuring the patients who may be worried or anxious or feel stigmatised about a diagnosis of UC		☐ Not relevant
Consideration that patient focus on functional symptoms post-flare may lead them to consider that treatment is not working		☐ Not relevant
Courses involving psychologists, dieticians, nutritionists helpful in sharing ideas from other fields of expertise with patients		☐ Not relevant
Stratification of patient in terms of risk of progression		☐ Not relevant
Whether the patient experienced a flare on optimised therapy		☐ Not relevant
Consideration of the severity of disease at initial diagnosis		☐ Not relevant
Lack of consistent evidence about a diet that is better for UC patients		☐ Not relevant
Sufficiency of endoscopically identified erythema as a guide for treatment		☐ Not relevant
Use of histological remission as an indicator for 5-ASA management		☐ Not relevant
Consideration of switching to other drugs from 5-ASA		☐ Not relevant
Evaluation of whether previous diagnosis of mild disease has been carried out correctly		☐ Not relevant
Consideration of non-steroidal anti-inflammatory drugs (NSAIDs) as a potential exacerbating factor		☐ Not relevant
Education of patients on importance of biomarkers in monitoring their disease post-flare		☐ Not relevant
Education of the patient that adherence to treatment contributes to staying in remission		☐ Not relevant
Measurement of the baseline level of faecal calprotectin		☐ Not relevant
Consideration of the history of disease before relapse		☐ Not relevant
Evaluation of patient reported outcomes		☐ Not relevant

Consideration of increasing rectal 5-ASA frequency		☐ Not relevant
Consideration of reducing the burden on health care system		☐ Not relevant
Consideration of whether treatment with 5-ASA will be enough		☐ Not relevant
Keeping patients on 5-ASA even while on biologic if they have a higher risk of colorectal cancer		☐ Not relevant
Consideration of the duration of remission before a flare		☐ Not relevant
Consideration of antibiotics as a potential exacerbating factor		☐ Not relevant
Engaging the patient in their management through education and understanding their disease		☐ Not relevant
Establishing contingency plans with the patient in case of relapse		☐ Not relevant
Consideration of the use of sigmoidoscopy to screen for dysplasia or colorectal cancer		☐ Not relevant
Taking account of limited data from Cochrane meta-analysis supporting high doses of 5-ASA		☐ Not relevant
Consideration of the patient's age		☐ Not relevant
Potential patient reticence to take azathioprine because of the risks of adverse effects		☐ Not relevant
Keeping on 5-ASA for maintenance		☐ Not relevant
Involving the nurse to help to inform the patient about red flags amongst symptoms and signs to be communicated immediately		☐ Not relevant
Discussion of other treatment options including dose optimisation if the patient is complaining		☐ Not relevant
Use of histological remission as a marker for lower risk of relapse		☐ Not relevant
Consideration of how to improve maintenance strategy by increasing dose		☐ Not relevant
Empowerment allowing for patients' differing points of view, perceptions, knowledge and abilities		☐ Not relevant
Confirm the flare is inflammatory disease not irritable bowel syndrome (IBS)-like symptoms		☐ Not relevant
The use of maintenance periods as a patient educational opportunity to cover future patterns, treatment options, surveillance and family risk		☐ Not relevant
Consideration that side-effects of 5-ASA may be more idiosyncratic than dose-related		☐ Not relevant
Perception that the milder the flare the more difficult the treatment decision		☐ Not relevant
Consideration of whether sigmoidoscopy is a priority and should be performed or not		☐ Not relevant
Consideration of hidden super-infections as a potential exacerbating factor		☐ Not relevant
After a second or third course of steroids whether 5-ASA may not be maintaining the patient well enough		☐ Not relevant
Whether the patient is on any other type of treatment for IBD		☐ Not relevant
Evaluate disease activity e.g. frequency of bowel movement, blood in stool, abdominal pain to guide treatment choices		☐ Not relevant
Relative effectiveness of generic 5-ASA versus commercial products		☐ Not relevant
Potentially reducing dose of 5-ASA because of cost risk of relapse		☐ Not relevant
Not going back to 5-ASA dose at which a flare occurred after remission unless the pattern of disease has changed		☐ Not relevant

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