

EFCCA Conference: What do IBD patients find important in their treatment?

Setting the scene, a physician's perspective

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Disclosures

- financial support for research from AbbVie, Biora Therapeutics, Celltrion, Landos, Pfizer, Sanofi, Sosei Heptares/Nxera, and Takeda.
- speaker's fees from Abbvie, Agomab, Biogen, Bristol Myers Squibb, Celltrion, Chiesi, Falk, Ferring, Galapagos, Janssen, Lily, MSD, Pfizer, R-Biopharm, Takeda, Tillots Pharma, Truvion and Viatrix.
- consultancy fees from Abbvie, Alimentiv, Applied Strategic, Atheneum, BenevolentAI, Biora Therapeutics, Bristol Myers Squibb, Eli Lilly, Galapagos, Guidepoint, Landos, Merck, Mirador Therapeutics, Mylan, Inotrem, Ipsos, Janssen, Pfizer, Progenity, Sandoz, Santa Ana Bio, Sosei Heptares, Takeda, Tillots Pharma and Viatrix.
- stock options Vagustim.

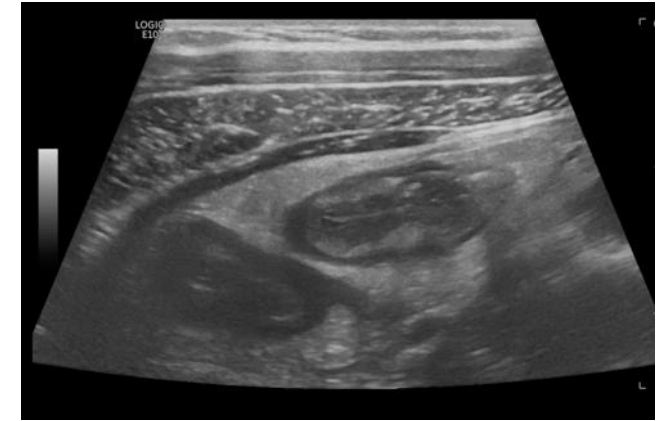
Setting the scene



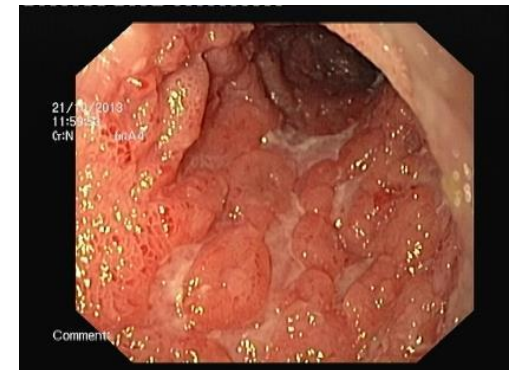
19 y old man

abdominal, crampy pain
bloody diarrhea, 8-10x / day and night
lost 5kg / 2 months

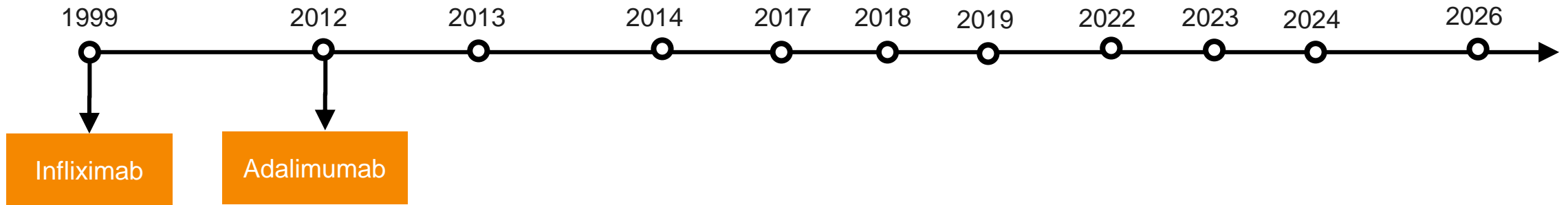
known with uncomplicated ileal Crohn's disease



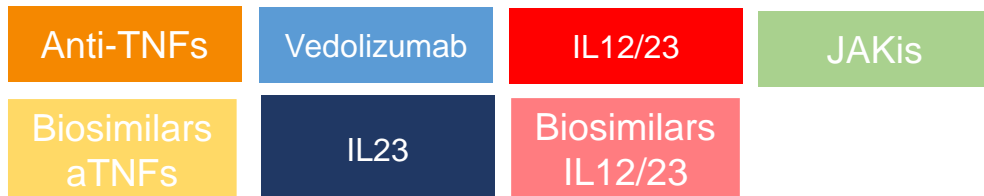
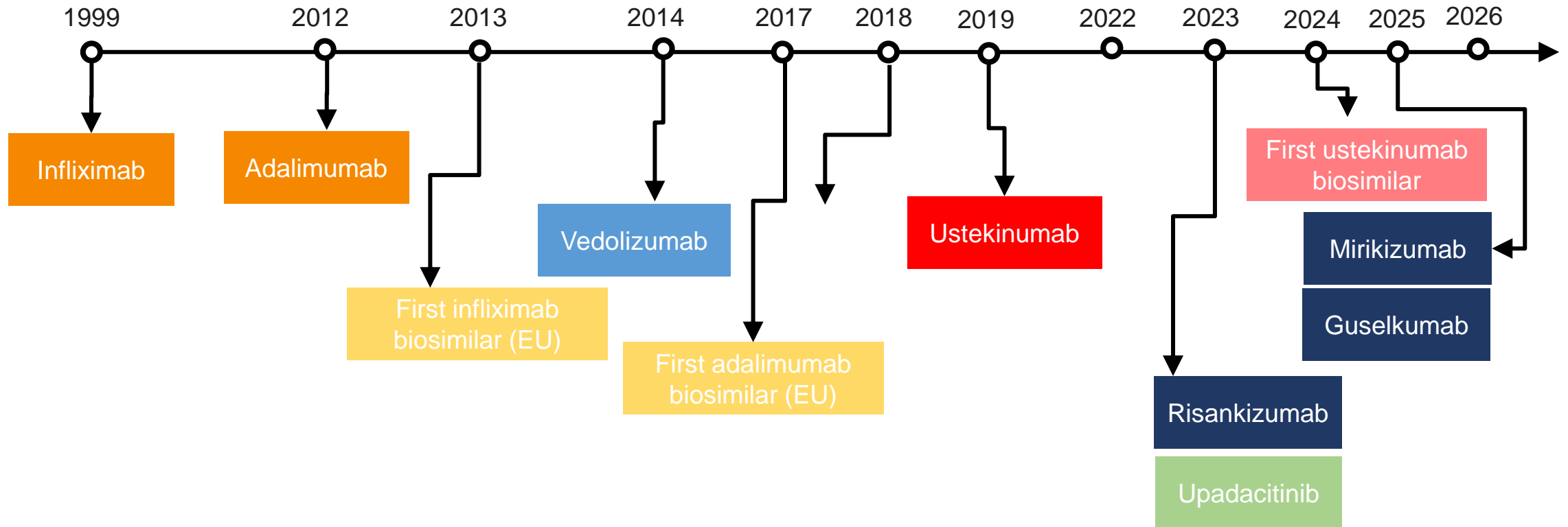
Uncomplicated ileal CD, 15 cm



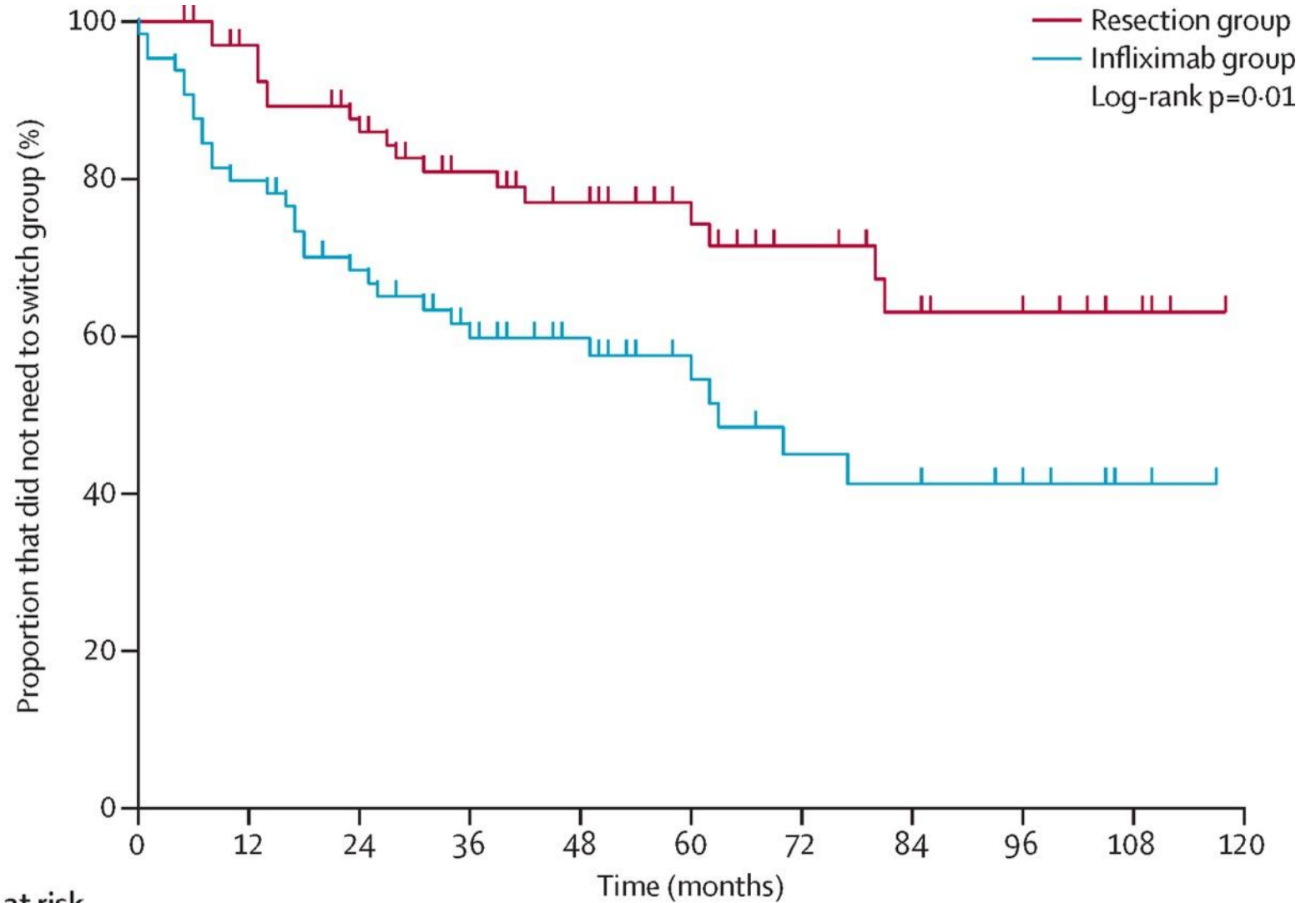
Setting the scene



Setting the scene



Setting the scene



**Number at risk
(number censored)**

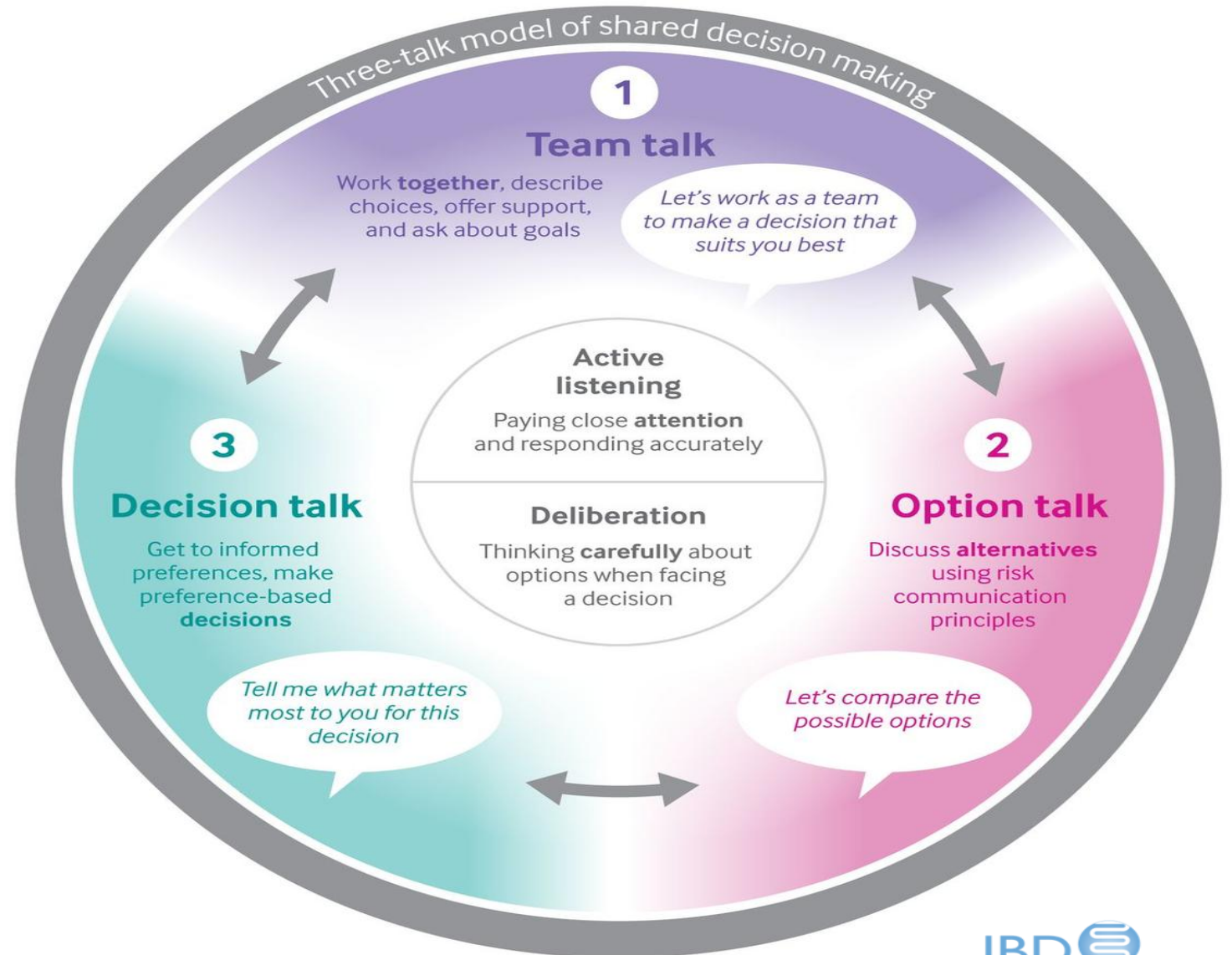
Resection group	69 (0)	63 (4)	54 (7)	43 (14)	37 (18)	28 (27)	20 (33)	14 (37)	12 (39)	6 (45)	0 (51)
Infliximab group	65 (0)	50 (2)	41 (4)	34 (7)	27 (13)	19 (20)	12 (23)	11 (23)	9 (25)	6 (31)	0 (34)

Setting the scene : shared decision making



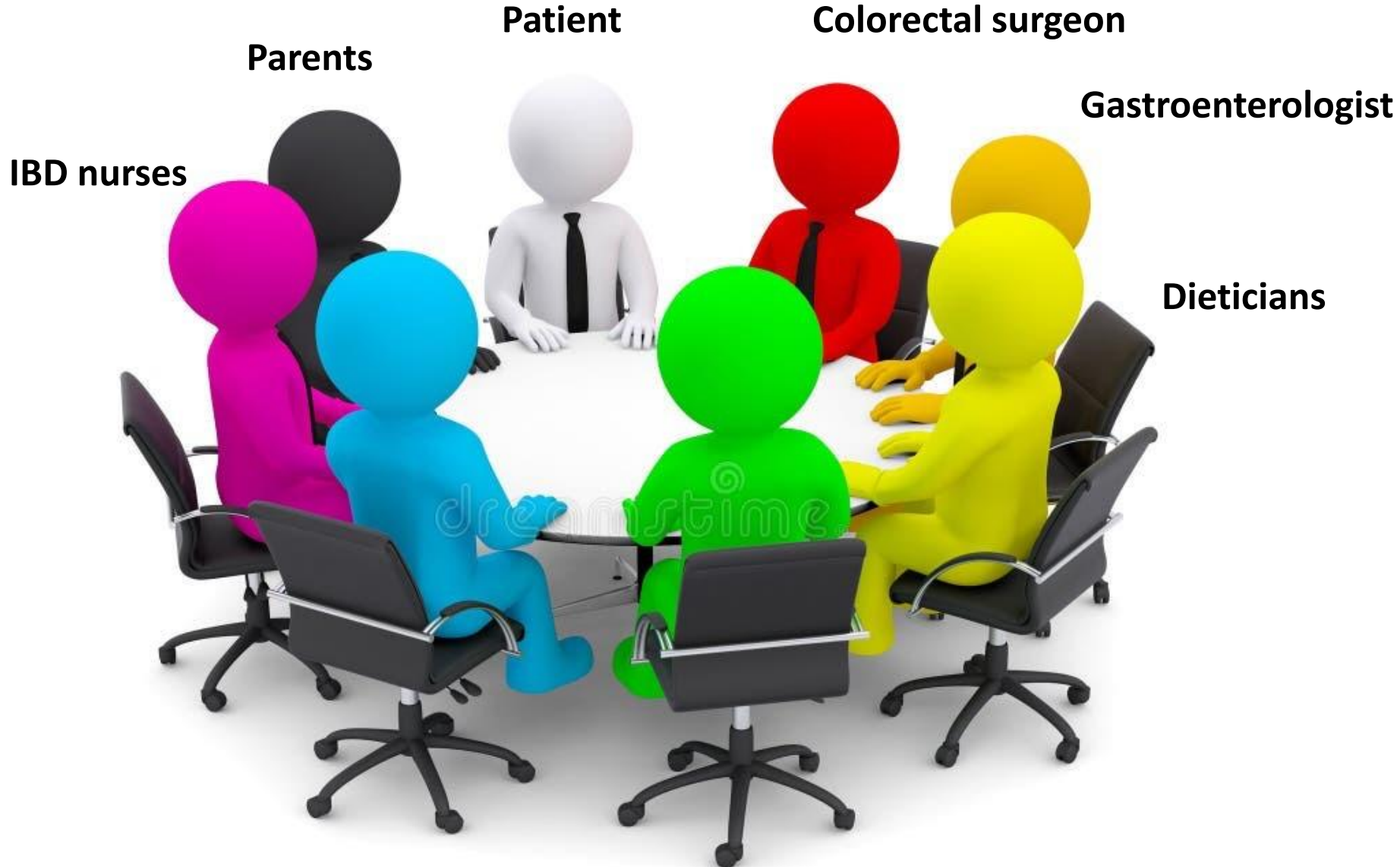
Shared decision-making (SDM) at a glance

Definition SDM: an approach where **clinicians and patients** share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options and to achieve informed preferences



How are we doing this at the IBD clinic in Leuven ?

Multidisciplinary IBD clinic



How are we doing this at the IBD clinic in Leuven ?

	MODE OF ACTION	BENEFICIAL EFFECTS OUTSIDE THE INTESTINE	EFFICIENCY & ADMINISTERING MEDICATION	NOTES											
BIOLOGIC TREATMENTS	<p>ACCESS TO THE MOST INNOVATIVE STUDY-BASED TREATMENTS. (PROBIOTICS, ANTI-INFLAMMATORY PILLS – INFUSIONS – SYRINGES, DIETS AND MORE). CONSULT YOUR PHYSICIAN.</p>														
	<p>ANTI-TNF</p>		<p>DAYS TO WEEKS</p> <p>INFLIXIMAB¹ (FLIXABI®, INFLECTRA®, REMICADE®, REMSIMA® EN ZESSLY®) TEMPORARILY COMBINED WITH IMURAN®, PURINETHOL®, LEDERTREXAAT® OR METOJECT®.</p> <p>4X 2X</p> <p>ADALIMUMAB (AMGEVITA®, HULIO®, HUMIRA®, HYRIMOZ®, IDACIO®, IMRALDI®, YUFLYMA®, HUKYNDRA®)</p>	<p>¹ ALSO POSSIBLE THROUGH SYRINGE</p>											
	<p>ANTI-ADHESIE</p>		<p>WEEKS TO MONTHS</p> <p>VEDOLIZUMAB¹ (ENTYVIO®) (☐) ONLY FOR CROHN</p>	<p>¹ ALSO POSSIBLE THROUGH SYRINGE</p>											
	<p>ANTI-IL12/23</p>		<p>WEEKS TO MONTHS</p> <p>○ RISANKIZUMAB (SKYRIZI®)¹ ● USTEKINUMAB (STELARA®)¹ ● MIRIKIZUMAB (OMVOH®)²</p>	<p>☐ ON BODY INJECTION</p> <p>¹ ONLY FOR CROHN</p> <p>² ONLY FOR ULCERATIVE COLITIS</p>											
	<p>ANTI-JAK</p>		<p>DAYS TO WEEKS</p> <table border="1"> <thead> <tr> <th>MEDICATION</th> <th>LOADING DOSE</th> <th>MAINTENANCE DOSE</th> </tr> </thead> <tbody> <tr> <td>TOFACITINIB (XELJANZ®)²</td> <td>10MG 2/DAY</td> <td>5MG 2/DAY</td> </tr> <tr> <td>FILGOTINIB (JYSELECA®)²</td> <td>200MG 1/DAY</td> <td>200MG 1/DAY</td> </tr> <tr> <td>UPADACITINIB (RINVOO®)</td> <td>45MG 1/DAY</td> <td>30MG 1/DAY OR 15MG 1/DAY</td> </tr> </tbody> </table>	MEDICATION	LOADING DOSE	MAINTENANCE DOSE	TOFACITINIB (XELJANZ®) ²	10MG 2/DAY	5MG 2/DAY	FILGOTINIB (JYSELECA®) ²	200MG 1/DAY	200MG 1/DAY	UPADACITINIB (RINVOO®)	45MG 1/DAY	30MG 1/DAY OR 15MG 1/DAY
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<p>SP MODULATORS</p>		<p>WEEKS TO MONTHS</p> <table border="1"> <thead> <tr> <th>MEDICATION</th> <th>LOADING DOSE</th> <th>MAINTENANCE DOSE</th> </tr> </thead> <tbody> <tr> <td>OZANIMOD (ZEPOSIA®)²</td> <td>0.23MG 1/DAY – DAY 1-4 0.46MG 1/DAY – DAY 5-7</td> <td>0.92MG 1/DAY</td> </tr> <tr> <td>ETRASIMOD (VELSIPITY®)²</td> <td>2MG 1/DAY</td> <td>2MG 1/DAY</td> </tr> </tbody> </table>	MEDICATION	LOADING DOSE	MAINTENANCE DOSE	OZANIMOD (ZEPOSIA®) ²	0.23MG 1/DAY – DAY 1-4 0.46MG 1/DAY – DAY 5-7	0.92MG 1/DAY	ETRASIMOD (VELSIPITY®) ²	2MG 1/DAY	2MG 1/DAY	<p>² ONLY FOR ULCERATIVE COLITIS</p>			
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Disease sub phenotype

Side effects?

Compliance?

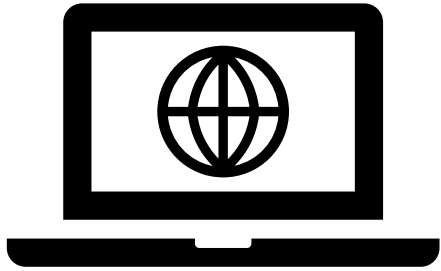
Speed of onset?

Co-morbidities?

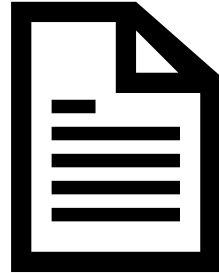
Severity?

Patient Decision Aid

Online tool



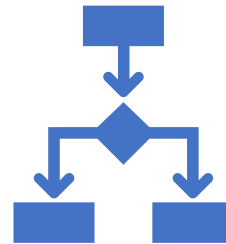
Paper-based tool



Aim: to i) make the decision that needs to be made *explicit*, ii) provide *evidence-based information* about the health condition, the options, associated benefits, harms, probabilities, and scientific uncertainties, and iii) *help clarify values* for features and outcomes of options

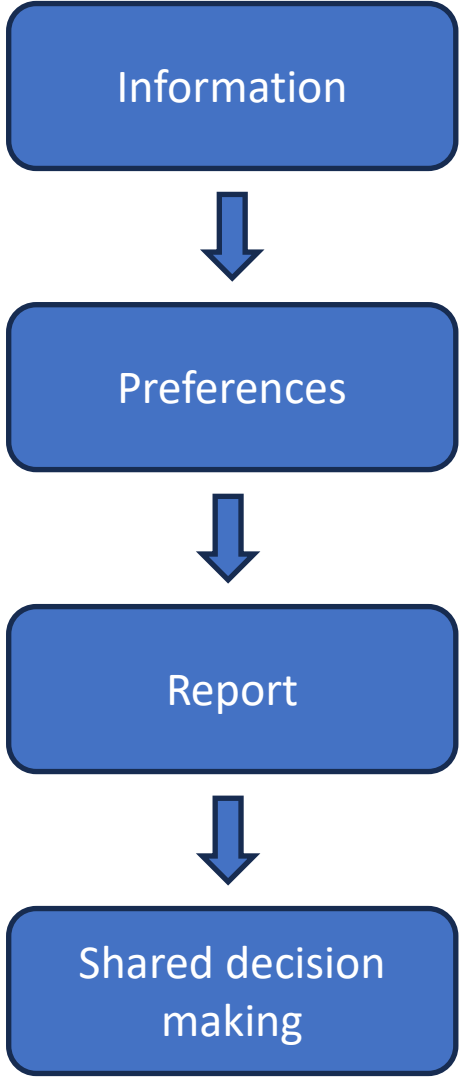


Increase knowledge



Decrease decisional-conflict

Patient decision aid (online tool)



What do you find important in therapy?

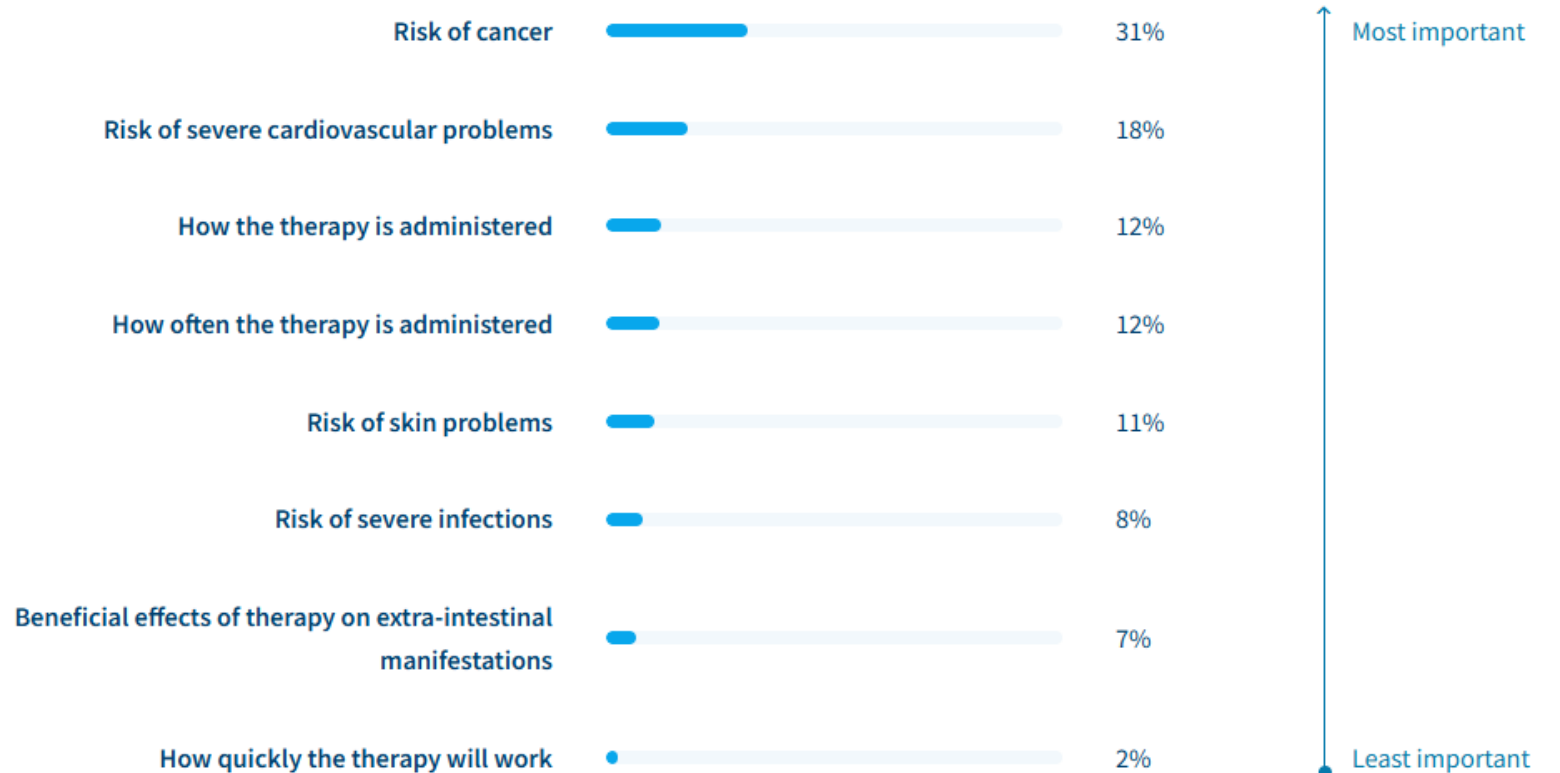
Complete the questionnaire

Which of the two therapies do you prefer?

Imagine that you and your IBD team are discussing treatments for your inflammatory bowel disease. Your IBD team thinks there are two possible treatments for you: treatment A and treatment B.

These aspects are important for you

Below you can see the scores of the 8 characteristics of the biologicals and small molecules that were examined during the questions. The higher the score, the more important you find this aspect when making a choice for therapy.



Conclusions

- Anno 2025, **SDM** should be considered **standard of care** to get **patients actively involved** in their treatment strategy, **increase compliance** and ultimately **improve outcomes**.
- There is a need for **SDM skills training** and **organizational changes**, such as the recognition and a more **strengthened role of the IBD nurse** in the SDM process.
- **Patients** signal their willingness to be involved in SDM.
- **Patient organizations** can have an important role in creating awareness about SDM among patients and in stimulating patient empowerment.
- **Patient decision aids** could stimulate SDM in practice, but further research is needed.

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