Planning to set up an IBD advice line?

Toolkit with questions to be asked prior to onset

Introduction

As every IBD centre has a unique structure and specific challenges it is not possible to present a final concept for an acute advice line (AL). On the contrary, the solution should be developed locally based on local conditions and priorities.

This toolkit intends to give an overview of topics and questions to be asked prior to setting up an acute AL in IBD.
The main topics are:

- Why set up an AL?
- Target group
- Concept
- Staffing/Workforce considerations
- Health economics
- Data collection

The toolkit will ask several questions and provide suggestions to some of them. Furthermore, different literature will be suggested.

We hope this toolkit will be useful in preparing an AL for IBD patients.
It is our intention that health professionals can work with the questions in a MDT setting.

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Why set up an AL?

The questions in this section outline considerations when setting up an acute advice line (AL) for patients with IBD. The aim is to frame the idea in an overall context.

Q-W1:
Why set up an AL?

Q-W2:
Are there unmet needs that an AL can solve?

Q-W3:
What is the problem?

Q-W4:
Can an AL solve the problem?

Q-W5:
What outcome is expected?

Q-W6:
Will an AL give a better quality of care?

Q-W7:
Who is asking for an AL?

Q-W8:
Who is sceptical?

Q-W9:
Who will fund the AL?

Q-W10:
Who will be responsible for establishing an AL?

Q-W11:
Who will be responsible for running the AL?

Q-W12:
Who will be responsible for evaluating the AL?

Break:
Please reflect based on the questions and your answers above.

Q-W13:
Do you still want to set up an AL in IBD?

Yes: go to **Q-T1**
No: no further actions required
Maybe: go through **Q-W1** to **Q-W12** again

Target group

Before introducing an AL it is essential to clarify the target group for the AL. The following questions focus on this topic.

Q-T1:
Who is expected to use an AL?

Q-T2:
Who is not?

Q-T3:
In which situations should an AL be used?

Q-T4:
Will an AL be acceptable by the patients?

Q-T5:
Have you asked the patients whether they would welcome an AL?

Q-T6:
Do you intend to ask them?

Q-T7:
How do you intend to educate patients in the use of AL?

Q-T8:
How can the patients prepare for a call to the AL?

Concept

This section will ask questions about how you imagine the AL will work.

Q-C1:
Will there be dedicated advice line sessions or will the calls be taken throughout all service opening hours?

Q-C2:
Who will initially take calls?

Secretary, IBD-nurse, other?

Q-C3:
If secretary, or foundational IBD nurse, will adequate training be provided regarding triage of urgency?

Q-C4:
If the IBD nurse is the first point of contact, what is the process for recording and documenting call and assessment?

Paper, electronically?

Q-C5:
When will the documentation take place (immediately during the call or retrospectively)?

Complete all records at the time of the telephone contact or as soon as possible afterwards

Q-C6:
How will plans of care and new clinical decisions be reported back to patients?

Within what time frame and by whom?

Q-C7:
If you have multiple nurses in your team, how will you allocate advice line time?

Q-C8:
Who will be responsible for checking messages and following up?

Q-C9:
How will this be documented?

Q-C10:
How will session or access times be advertised to patients?

Q-C11:
What instructions will be given to patients via voice message when the phone goes unanswered?

Q-C12:
What is the timeline for returning calls?

Q-C13:
Do you have an IBD nurse cell phone that patients can call and/or SMS?

Q-C14:
If so, who is responsible for this? How are calls logged? How is clinical content of calls documented?

Q-C15:
If returning calls, how many times will you attempt to call patients back (if they are not answering your call)? How will this be documented?

Q-C16:
During periods of nursing leave (expected or unexpected), who will be responsible for the advice line?

Q-C17:
Are there any guidelines of your hospital/organisation regarding non-F2F communication/tele-health/SMS-communication with patients?

Infrastructure & equipment

Q-C18:
Do you already have the equipment you need?

Phone handset, mobile phone, computer with internet access, printer & scanner, voicemail capability

Q-C19:
If not, how do you go about getting it?

Q-C20:
Do you need to apply to the organisation to get equipment set up?

Q-C21:
Do you have a dedicated e-mail address that you can use for AL-mail only, or does this need to be set up?

Q-C22:
Who will be responsible to maintaining equipment?

Others

Q-C23:
Will the IBD nurse, who answers the calls, have permission to recommend/prescribe/change the patients' medication?

Q-C24:
Have you visited another IBD centre for inspiration?

Staffing/Workforce considerations

Successful implementation of an AL requires an engaged, competent and well informed staff. This section asks questions about: support, workforce, environment, communication, feedback & supervision.

Support

Q-S1:
Overall, is the organisation willing to support the advice line?

Q-S2:
If not, why?

Q-S3:
Will the AL be acceptable by any health care professionals in the MDT?

Workforce

Q-S4:
What is the number of total nursing hours per week within the IBD service?

Q-S5:
What number of nursing hours can be dedicated to the advice line per week?

Q-S6:
Will the advice line run for certain sessions daily, or all day?

Q-S7:
Is this dependent on number of nurses in the team (or maybe the number of patients)?

Q-S8:
Is there administrative support (secretary) for the advice line?

Q-S9:
What is the role of the secretary with regards to the advice line? If any?

Q-S10:
Are the IBD consultants and trainees supportive of the advice line?

Provide advice to patients only if you are suitably qualified and if you have adequate knowledge of that person's health and medical history. Wherever possible the nurse conducting the telephone service should always ensure they have access to the patients' medical records at the time of telephone contact to enable an accurate consultation based on the patient's history

Q-S11:
Are the medical staff willing to be involved with the advice line during periods of nursing leave?

Q-S12:
Is the medical staff willing to approve nurse-led orders and plans of care?

Q-S13:

Will the advice line have an answering machine to take messages or will it be manned by a person?

Environment

Q-S14:
Is the advice line run in a shared office?

Q-S15:
If yes, with who?

Q-S16:
Is the office space suitable to have discussions with patients that may be sensitive in nature?

Q-S17:
Is there a dedicated phone line for the advice line?

Q-S18:
Is there a cell phone available for call diversions?

Q-S19:
If in a single office space, can calls be otherwise diverted?

To whom?

Q-S20:
Are medical records and other relevant information required for thorough nursing assessment easily accessible?

Paper format or electronically

Q-S21:
Is the template used for nursing assessment easily accessible?

Q-S22:
Is there a dedicated email access readily available to IBD patient?

Communication

Q-S23:
What communication skills are required for successful nursing consultation via the advice line?

Active listening.
Thoughtful questioning (asking curious/open ended questions, eg: can you tell me more about that? What do you mean by that?)
Conversely, asking targeted & specific questions to elucidate specific information (eg: can you further describe the pain for me? Have you had blood with each bowel motion?)
Asking 'clarification' questions
Asking the patient if they have any questions

Q-S24:
What other nursing skills can assist with communication via the advice line?

Extensive knowledge of disease (disease course, treatment options, side effects, EIMs assessment with consideration to disease location, severity, results of recent investigations, flare vs. differential symptom assessment)
Critical thinking and analysis
Acute problem solving
Accurate documentation
Understanding of the communication level of the patient (eg. patient who is difficult to get information from vs. patient who will tell the nurse every detail)
Building of rapport when seeing the patient face-to-face will make telephone/email communication easier

Feedback & supervision

Q-S25:
How will clinical advice be provided to a foundational IBD nurse for advice line calls?

Q-S26:
How will the foundational nurse be supervised when taking calls via the advice line?

Direct supervision from advanced IBD nurse during advice line session
Novice nurse consults advanced nurse after each advice line call
Novice nurse discusses all calls with advanced nurse after advice line session
Novice nurse emails advice line assessment form to advanced nurse for feedback when completed

Q-S27:
How will feedback be provided to the foundational nurse regarding advice line calls?

Advanced nurse listening in to calls and providing feedback
Structured feedback sessions using examples of calls managed by novice nurse

Q-S28:
Will feedback or supervision be provided to the advanced IBD nurse?

Advanced IBD nurse colleague = clinical supervision
IBD consultant

Health economics

If possible, it could be useful to consider how to generate data for economic analysis of the AL. Economic analysis can have different approaches. Some distinguish between direct and indirect costs.
Other distinguishes between 4 different health economic analysis:

Budget impact analysis (BIA). Focus is on the 'out of pocket' costs

Cost-effective analysis (CEA). Cost and health outcome is compared directly and a ratio is calculated

Cost-utility analysis (CUA). Focus is on gained health/HRQoL often calculated using patient reported quality-adjusted life-years (QALYs)

Cost-benefit analysis (CBA). Patients are asked to value an intervention (often compared to another). Can be expressed in 'willingness to pay'.

If you consider adding health economic analysis to your AL intervention, you should decide what data is needed for the specific analysis you will use.
Please also answer the questions in the 'data collection' section.

Regardless of health economic analysis, you can consider the following questions.

Q-H1:
What are the costs (economic, human resources) in the start-up phase?

Q-H2:
What are the ongoing costs associated with running the AL?

Q-H3:
How to document possible cost savings by running an AL?

Ask the department or hospital managers what they consider to be a valid documentation

Q-H4:
Would it be possible to ask the patients how much they appraise the AL (willingness to pay)?

You could simply outline 2 alternatives: 1) service without an AL and 2) service with an AL. Ask the patients how much they are willing to pay for option 2) compared to option 1) – if they should pay themselves, which is not the case (this part often needs some explanation)

Data collection

If you (or your organisation) will document any effect or impact of the AL, you must collect data systematically. A strategy for data collection must be determined before commencing the AL.
Some data must be collected prior to the introduction of the AL and some data while the AL is up and running.
Furthermore, specific data for health economic analysis might be collected. See the 'health economic' section. Finally, there might be some data and/or ethical issues around data collection.

Prior

Q-D1:
What data should be collected prior to the commencement?

Number of outpatient visits (per month and per year)
Number of patients yearly seen
Number of admissions
Emergency visits
Hospitalisations
Length of hospitalisation

Q-D2:
How could you collect the data?

Electronically, maybe with support from IT-people

Q-D3:
Why collect data prior to the commencement?

During

Q-D4:
Which outcomes should/could be measured when running the AL?

Disease activity
Health-Related Quality of Life (HRQoL)
Patient satisfaction
Time to treatment (in case of relapse)
Number of patient-nurse contacts
Number of patient-GE contacts
Number of patients not showing up
Number of acute/unplanned visits
Total number of contacts
Health economics

Q-D5:
How will you measure the data to be collected when running the AL?

Disease activity
HBI
SCCAI
Partial Mayo-score

CRP
F-calprotectin
HRQoL
SIBDQ
SHS
Patient satisfaction
Ad hoc scale
VAS-scale
Time to treatment (in case of relapse)
Data from the e-journal
Number of patient-nurse contacts
Collected onsite or in e-booking
Number of patient-GE contacts
Collected onsite or in e-booking
Number of patients staying away from appointments
Collected onsite or in e-booking
Number of acute/unplanned visits
Collected onsite, e-journal
Total number of contacts
Collected onsite or e-booking
Duration of telephone contact
Duration of documentation after a contact
Health economics
Health service used
Staff resources used
Patient-costs saved (time, travel, parking etc.)

Q-D6:
Why collect these outcome measures?

So far, evidence for ALs is scarce (Bager et al, Scand J Gastroenterol, 2018). By measuring specific outcome measures in a standardised way, it will be possible to find evidence for advice lines in IBD.
To be used both locally at your hospital and broader as evidence for the possible effect of ALs.

Q-D7:
How can you collect the data?

By use of a standard template for each patient contact. This can be different for each country and hospital. It is important to follow institutional or country specific reporting guidelines

Q-D8:
When to measure?

Before and one year after full implementation
Maybe summarise data on an annual basis

Approvals

Q-D9:
Is approval from the ethics required for the planned activity?

Q-D10:
Is approval from the data protection agency required for the planned activity?

Abbreviations

AL	Advice line
BIA	Budget impact analysis
CBA	Cost-benefit analysis
CEA	Cost-effective analysis
CRP	C-reactive protein
CUA	Cost-utility analysis
EIM	Extra intestinal manifestation
F2F	Face to face
GE	Gastroenterology
HBI	Harvey-Bradshaw index
HRQoL	Health-related quality of life
IBD	Inflammatory bowel disease
MDT	Multi disciplinary team
QALY	Quality-adjusted life-years
SCCAI	Simple Clinical Colitis Activity Index
SHS	Short Health Scale
SIBDQ	Short Inflammatory Bowel Disease Questionnaire
VAS	Visual Analogue Scale

Further reading

Bager P, Chauhan U, Greveson K, Jäghult S, Moortgat L & Kemp K. Systematic review: advice lines for patients with inflammatory bowel disease, Scand J Gastroenterol. 2018;53,506-512. DOI:10.1080/00365521.2017.1401116

Drummond MF, Sculpher MJ, Torrance GW, O'Brian B, Stoddart GL. Methods for economic evaluation of health care programmes. 3nd Ed. 2005. Oxford University Press; Oxford.

Royal College of Nursing. Using telephone advice for patients with long-term conditions: an RCN guide to using technology to complement nursing practice. 2012, Royal College of Nursing; London.

The Royal College of Nursing. Roles descriptives for inflammatory bowel disease nurse specialists - RCN guidance. 2007, The Royal College of Nursing; London.

'The Telephone Advice form' from Hamilton Health Sciences, McMaster University Medical Centre Hamilton, Ontario, Canada. See attached.

IBD Telephone Advise form

1. **Date and time of call:** **Call conducted by: Nurse, Admin Assistant**
2. **Name:**
3. **Telephone #**
4. **Hospital #**
5. **Caller:** Patient, Spouse, Parent, Child, Friend: _____, Other:_____
6. **Last Clinic visit:**
7. **Type of IBD**

Ulcerative Colitis	Crohn's Disease	Undifferentiated Inflammatory Bowel Disease

8. **Reason for call:**

Disease Flare	Recent Hospitalization
Other GI symptoms	Medication Concerns
Investigation Results	Scheduling appointments
Symptoms update	Psycho-social concerns
Lab requisition	Other: _____

9. In general, how would you rate your health today? (Please circle)
1=Very good; 2=Good; 3=Moderate; 4=Bad; 5=Very bad

10. How is your wellbeing (Please circle)
0=Very good; 1= Slightly below average, 2=Poor 3=Very Poor 4=Terrible
11. ***Thinking about the last 24 hours*** *have* you had abdominal pain _____NO ____YES
If yes: (Please circle)

0	*1*	*2*	*3*
None	*Mild*	*Moderate*	*Severe*

12. ***Thinking about your bowel movement***
    a. How many bowel movement have you had? _____
    b. How many of these were liquid stools?(if applicable) _____
    c. Do you experience urgency with your bowel movements? _____NO ____YES
    if yes, rate your urgency: none / hurry / immediately / accidents
    d. Do you have any rectal bleeding? _____NO ____YES
    e. Do have nighttime bowel movements? _____NO ____YES

Since the last clinic visit

13. **Have you lost any weight**? _____NO ____YES. If yes, how much? _____kg _____lbs

14. **Do you have any vomiting**? _____NO ____YES
15. **Do you experience any discharge/drainage around the anal area**?_____NO ____YES
16. **Do have any perianal pain?** _____NO ____YES
17. **Do you have any new skin problems** _____NO ____YES
18. **Have you had a fever?** _____NO ____YES
19. To what extent do you feel your GI symptoms interfere with your day to day life and functioning?

0	1	2	3	4
Very poor	Poor	Neither poor nor good	Good	Very good

20. Current Medication:

21. Are you taking the medication as prescribed? Yes/No.
If no, when did you last take the medication or how many doses do you miss per week?

22. Assessments and diagnosis:

23. Plan and Action

Provide nurse managed care	Schedule appointment in IBD clinic
Schedule investigation	Consult primary health care practitioner
Change medication	Go to Emergency Department
Call in prescription	Continue with current plan
Schedule telephone call to reassess	Other: _____

24. How satisfied are you in general with the information that you have received?

Extremely satisfied	very satisfied	satisfied	Moderately satisfied	Slightly satisfied	Not satisfied at all

25. Length of call

<5 minutes 5-10 minutes 10-15 minutes 15-20 minutes

20-25 minutes 25-30 minutes > 30 minutes