JOIN.the.DOTS In.SBS-IF

Guidance to support effective multidisciplinary teams (MDT)

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For healthcare professionals only.

JOIN.the.DOTS In.SBS-IF

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Introduction

Welcome to the 'Join the Dots in SBS-IF' toolkit which has been designed to provide you with the information and tools needed to support you in setting up effective multidisciplinary teams (MDT) which can help optimise your clinical practices and provide optimal care for patients living with short bowel syndrome with intestinal failure (SBS-IF).

Effectively using this toolkit

We recognise that different clinical teams have different structures and resources. You may or may not have an existing MDT for SBS-IF care, or your MDT may be at a different stage of development to others. While there may never be such a thing as the 'perfect' MDT, this toolkit has been designed to support you in building an effective MDT and optimising SBS-IF care in a manner that is relevant to you.

Therefore, whatever stage your MDT for SBS-IF care is at, read through the guidance document and use the tools/materials and best practice case studies within the toolkit that are relevant in helping build the best team for you.

We hope you find this document to be of use, and please do not hesitate to contact us if you have any questions and need support with any of the activities or processes outlined below.

Please also remember to share your experience with your local Takeda team so we can in turn share your successes with a wider audience. Your efforts and outcomes will help to guide and inspire other HCPs. If you have a success story that you would like to share, please get in touch.

On behalf of Takeda, we wish you the best of luck in your activities and look forward to hearing about your successes!

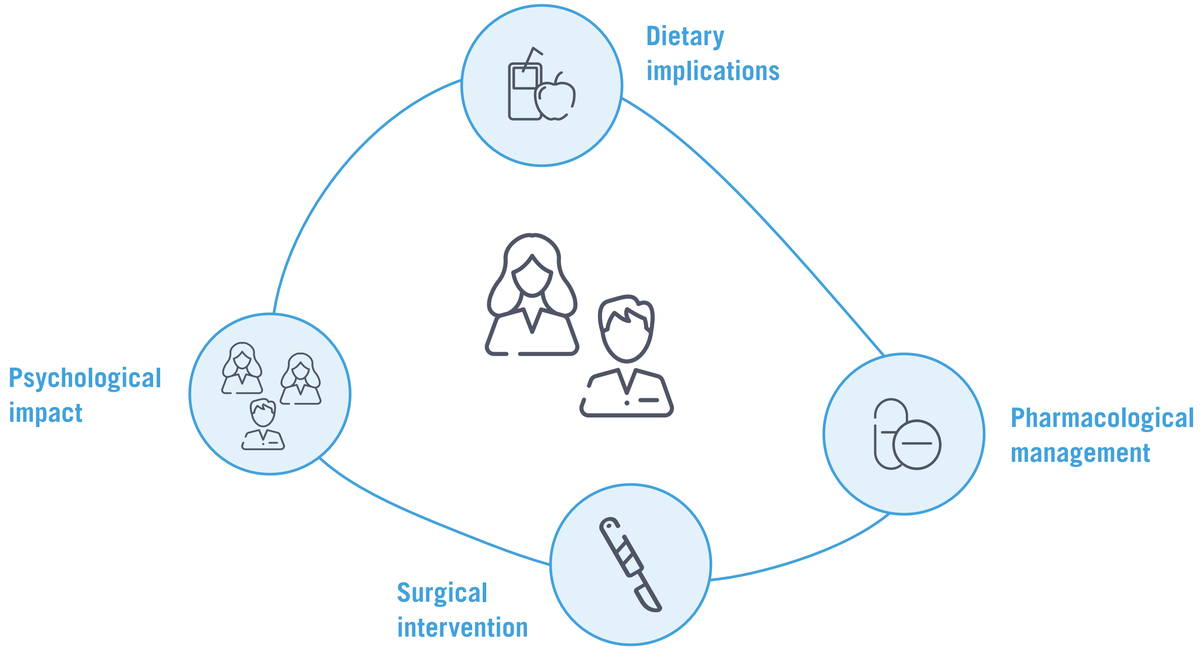
Kind regards

GI Team Takeda

About short bowel syndrome with intestinal failure (SBS-IF) and the challenges faced

SBS-IF is a challenging and often disabling condition associated with significant morbidity and mortality, reduced quality of life and high healthcare costs.[1]

The reason for SBS-IF being so complex is partly due to the variety of ways in which it can present itself, with the clinical manifestation and outcome of SBS-IF being varied based on a number of factors including anatomy and function of the remaining bowel, the age of the patient, the primary disease process, comorbid diseases and the presence of chronic intestinal obstruction.[1]



People with SBS-IF can suffer from a wide range of symptoms including clinical manifestations as well as psychological and social issues.[1,2]

Due to these wide range of symptoms, multiple approaches are needed to manage SBS-IF, including dietary, fluid and pharmacological management, co-morbid disease management and, occasionally, surgery.[1]

The value of a MDT for short bowel syndrome with intestinal failure (SBS-IF)

The need for multiple management approaches for SBS-IF as described in the **'About SBS-IF'** section makes treatment of patients more challenging by a single individual and requires experts from different disciplines to ensure that patients with SBS-IF are being treated optimally.

Therefore, a multidisciplinary approach consisting of physicians, dietitians, surgeons, specialist nurses and psychologists who are experienced in the care of these patients is optimal.

While a **gastroenterologist** may be responsible for overseeing the care of the patient, a **nutritionist** is better placed to support the patient in finding the correct nutritional approach especially when any modifications in parenteral nutrition (PN) are required.

A **specialist nurse**, for example, can support the patient and their family by providing ongoing guidance about how to best manage their condition whilst they are an in-patient as well as an out-patient.

A **surgeon** can be involved in treatment decisions as well as provide surgery, if needed. They may also play a role in referring the patient to other members of the team or to other specialist centres for follow up care.

Other disciplines can also add value to the SBS-IF patient as part of a MDT. Further details on the disciplines that can be involved in the care of SBS-IF patients are provided in the **'Key Dimensions of a MDT'** section.

Involving multiple clinical disciplines in patient care can also add to the patient's sense of being the nucleus of their care 'solar system' and the central party in the MDT's decision making. Learn more about how a holistic plan can benefit patients in the **'Patient case studies'** section.

In addition, a multidisciplinary approach allows for potential cost savings as it can help provide a full overview of what is happening, so it is clear when to start and stop treatments.

Importance of shared decision making

Shared decision making is when a HCP and patient share information, build a consensus and agree a decision.[3]

Due to the complexities involved in SBS-IF, it is important for patients to be effectively counselled regarding decisions in the management of their condition so they can understand the treatment options available to them and become a 'collaborator' in their own care.

Consider using the 5-step SHARE Approach summarised by the Agency for Healthcare Research and Quality (AHRQ) for effective shared decision making:

1. **SEEK** your patient's participation
2. **HELP** your patient explore and compare treatment options
3. **ASSESS** your patient's values and preferences
4. **REACH** a decision with your patient
5. **EVALUATE** your patient's decision

Agency for Healthcare Research and Quality. [Accessed: July 2020];The SHARE approach: 5 Essential Steps to Shared Decision-Making.2014 at http://www.ahrq.gov/professionals/education/curriculum-tools/shareddecisionmaking/index.html. Last accessed: August 2020.

Importance of shared decision making

Shared decision making opens conversations between HCPs and patients, empowers patients to make informed choices about their treatment and care, and also helps HCPs align on treatment strategies to avoid confusing messages to the patient. It helps patients become independent and take responsibility for managing their own care, as highlighted in the visual below.

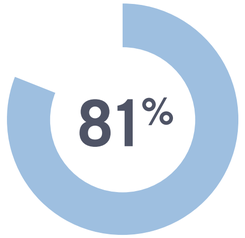
Patients gain a better **understanding** of their disease and management plan

Greater **acceptance** of their disease and their management plan

Increased engagement with their management plan and improved medication **adherence**

Increases **trust and credibility** of treating centre/physicians

Improved **clinical and quality-of-life outcomes**



Results from an online survey of 1,067 Dutch IBD patients[3] showed that **81% of respondents felt joint-decision making was very important to them**.

This suggests that the majority of patients want to provide input into their treatment and care plan. Shared decision making can not only improve outcomes for patients, but it can also increase physician satisfaction as a result of feeling that they are also supporting with listening to their patients while providing high-quality care.

Key dimensions of a MDT

MDTs are recognised as being an effective way of improving outcomes in SBS-IF patients, however, we understand that different centres have differing levels of resource and skillsets. It is, therefore, important to remember that bringing together an effective MDT does not mean you have to wait for the perfect conditions to form a MDT. The key is ensuring that a pragmatic solution is found that works for the centre, is fit for purpose and will improve outcomes more than the current delivery of care.

A dedicated leader or care co-ordinator, as you will see outlined in the **Austrian case study**, who acts as a central, continuous point of contact for the patient and the range of professionals involved in the care package, can help improve the success rate of a MDT

Outlined below is a brief outline of key members that can work together to care for a SBS-IF patient.

Gastroenterologist –
responsible for overseeing the care of the patient, establishing the treament approach with the patient

Surgeon –
working closely with the gastroenterologist and other members of the MDT, a surgeon can help make decisions about treatment, referral and management related to referral

Specialist Nurse –
often the most frequent point of contact, the nurse provides support for the patient as well as family members, administers parenteral nutrition and importantly provides ongoing education and information to the patient and their family to help them care for themselves

Dietitian –
plays a crucial role by helping the patient find the correct nutritional profile, monitors the patient's weight, diet and checks their blood stools every month, optimising the patient's nutrition

Psychologist –
SBS-IF can have a significant emotional impact on a patient and their families, and a psychologist can help manage the emotional well-being of the patient and if necessary, their family

Radiologist –
the largest part of the small bowel can only be evaluated through certain imaging methods and therefore a radiologist is needed in the initial evaluation as well as in the periodic follow-up of SBS-IF patients to assess the clinical progression of SBS-IF patients

Pharmacist –
due to SBS-IF being a malabsorptive condition, the form and posology of the treatment is important. Pharmacists play a role in ensuring medicines are absorbed appropriately. Additionally, patients may have other comorbidities, so the pharmacist has an important role to play to avoid use of contra-indicated treatments

Insights gained from the MDT at the Vienna General Hospital (AKH) in Austria

Key barriers to consider

Before establishing your MDT, it is important to understand some of the key barriers that you could face so you can prepare to address them.

> Consider connecting with peers and colleagues who have worked as part of a multidisciplinary team to identify key barriers and learn from past experiences

Some identified challenges include:

- **Time and effort:** SBS-IF patients require a lot of time and effort initiating treatment sometimes with little to no payoff. Financially, this can be viewed as unrewarding
- **The idea of a perfect MDT:** The perception that only a large, formal MDT is effective can create a barrier for clinicians and internal staff/hospital management who are trying to encourage other clinicians
- **Securing buy-in and resources:** Getting initial buy-in from the hospital and administrative staff as well as getting adequate resources can be challenging
- **Building the team:** Finding and securing the most qualified people to interact with, can take time and motivating colleagues requires additional effort from the lead physician and other specialties
- **Clear management and guidelines:** Lack of awareness about existing guidelines can cause delays in a SBS-IF patient being seen by the appropriate person/team for the right treatment
- **Identifying patients with complex needs:** This could prove to be a barrier/challenge when there is not enough awareness of the condition and triggers where care should be escalated
- **Clear purpose and communications:** Lack of a unified goal/aim across different disciplines can lead to siloed working resulting in a fragmented approach

Insights gained from the MDT at the Vienna General Hospital (AKH) in Austria

Establishing/enhancing your centre

The information in this section aims to show what different MDTs could look like and to support the set-up and development of a MDT in your area. It is important to note that the different types of MDT outlined in this section are a description and not a fixed approach, and they will differ across teams and geographies.

A set of best practice examples based on these scenarios adopted by three countries can be found in **this** section. Different centres will likely be at different stages in terms of having a MDT to care for SBS-IF patients and while these case studies will help provide an overview of developing an effective MDT, it is important for you to use the information that is relevant to you.

Types of MDT

Fundamental MDT

This set-up is where a single health professional coordinates an informal multidisciplinary approach by motivating and bringing in other professionals from the centre to care for a patient with complex needs. It might be characterised by one professional upskilling and training other professionals to be part of a team and input into care planning on an irregular basis. Team meetings may not be formalised, and communication doesn't tend to be frequent but takes place as needed. This generally includes personal development and learning plans to develop skills of professionals involved. **View the best practice example from Norway.**

Advanced MDT

This includes the set-up of a large, dedicated core team consisting of several different disciplines who work closely to care for a patient and tailor services based on their needs. The members of the team are generally able to commit to high levels of resources towards the smooth functioning of the team. It generally includes clear structures and processes to achieve results and team members have clearly defined roles and responsibilities. **View the best practice example from Austria.**

Functional MDT

This is where a MDT is initially set-up with a minimum number of professionals and expands to a larger team over time. Collaborative working tends to be higher and is accompanied with a constant flow of communication. This type of MDT can include partnerships with local advocacy organisations and/or professional societies and may have been established based on a business case put forward to the hospital management, due to the lack of documented information or to address potential gaps in the current system. **View the best practice example from Ireland.**

Making it happen – a step-by-step guide to implementing a MDT in your centre

Use this poster as a reminder or a useful resource to build your own MDT from scratch.

1. **Assess the situation:** Understand the clinical and business needs to build a solution that meets existing (and potential future) needs. Agree on the benefits you are trying to realise which form the measures against which the success of the project can be measured

2. **Define your purpose:** Having assessed the situation, think of your key objectives and identify the actions required to take it forward

3. **Build a case:** Establish which key stakeholders need to be involved and get them on board as early as possible by presenting your case and the outcomes you want to achieve. Support case by collating qualitative and quantitative data*

4. **Identify patients:** Identify patients who would benefit from a holistic care plan. Consider asking them to complete a questionnaire at the outset to benchmark their satisfaction levels a few months later

5. **Set up your MDT structure:** Identify members and agree on the core membership based on the centres' and patient population needs

6. **Agree roles and responsibilities:** Once the group is established, agree on roles and responsibilities to support effective working. For example, assigning co-workers with clear responsibilities to manage patients instilled a sense of accountability in the case of the team in Norway as seen in the case study **here**

7. **Establish processes:** Upon agreement of the core membership, develop a local project implementation plan, and coordinate regular meetings

8. **Capture results:** Set up clear processes to obtain tangible data/outcomes on impact made by the team. Refer to the Austrian case study to see the type of data captured in the Outcomes section

9. **Ongoing review:** Set-up a process to constantly review successes and challenges within a specific timeframe to share feedback and impact with the team, hospital administration and other key stakeholders

***For a positive outcome, ensure your business case clearly outlines:**

- Background and context
- Purpose of the case
- An overview of the current services
- Why there is a need for change
- Requirements to establish a MDT
- Budgetary and resource requirements
- Key performance indicators (and how you will achieve them)
- MDT implementation model

Insights gained from various sources including expert meetings with HCPs, advisory boards, round tables and market research

Quick dos and don'ts guide

Use this list as a reminder or a useful resource for your own MDT.

Do	Don't
Do…start as early as possible, do your research on the current needs and involve appropriate stakeholders well in advance	Don't…presume stakeholders will be open to supporting you. Due to factors such as costs and resources, some stakeholders might need more information to fully understand the benefits and value of a multidisciplinary team
Do…understand the clinical and business needs and how the multidisciplinary approach can help achieve them	Don't…focus on task-orientated team working but on integrated working for successful collaboration
Do…learn from those that have already implemented successful multidisciplinary approaches	Don't…assume that team members are fully aware of other team members' roles and responsibilities or strengths and weaknesses
Do…include quantitative as well as qualitative data to strengthen your case for health executives/hospital administration or other important stakeholders	Don't…underestimate the value of developing working partnerships with peers, voluntary sector organisations, carer support, mental health units and other hospital units.
Do…use key messages and resources to share with the team for a unified message	Don't…have shared decision making as a separate programme; ensure it is incorporated in the overall multidisciplinary plan
Do…encourage teams to learn from each other to help understand the different roles and responsibilities within the MDT	Don't forget… patients and communities are a key resource and can be trained to deliver much of the self-management support needed
Do…set key objectives and an agreement on what success looks like at the outset of the project	

Insights gained from various sources including expert meetings with HCPs, advisory boards, round tables and market research

Top 10 essentials to strive for in a MDT

Use this as a reminder or a useful guide to deliver high-quality patient services.

1. Comprises a **good mix of disciplines** and operates from one location so that the patient views each expert as part of their core team who work together, coordinate and deliver services to achieve the best outcomes
2. Provides **holistic and patient-centred care** to encourage patients to become informed and able to self-manage their condition so they can live with their new normal
3. Listens, offers open and **continuous lines of communication** and works around the needs of people and their families
4. Invites patients (and potentially families/carers if requested) to **feed into their treatment and care plan** so they feel part of the core team and decision-making process
5. Develops integrated plans which includes the **patient's specific needs,** lifestyle, goals and aspirations
6. Commits themselves to **close working, actively participating** and maintaining constant flow of communication between all disciplines
7. **Pools expertise and skills** from multiple disciplines and recognises the value of learning and combining skills of MDT members to work as ONE team
8. Includes **strong leadership** who drives and continuously improves MDT working, as well as provides support at a strategic/management level
9. Demonstrates **good understanding and up-to-date knowledge of SBS-IF** and the complexities associated with the condition, and if necessary, coordinates educational/skill-sharing sessions amongst team members
10. Has a shared vision and a plan to **track measurable outcomes,** both service and patient related

Insights gained from various sources including expert meetings with HCPs, advisory boards, round tables and market research

Measuring success and sharing best practice

Measuring and evaluating success from your project is crucial as it helps to assess success and provides a measurement against objectives. It also provides a reference for future activities and can form part of a best practice case study.

Improved patient outcomes and quality of life are strong indicators of a MDT which is functioning successfully. Happy MDT members are also indicative of a successful team. As such, think of capturing these outcomes by:

- Asking patients to complete a questionnaire aligned with your MDT's key objectives at the start of the care plan and then asking them to complete another questionnaire 12 months later to benchmark progress
- Conducting an annual audit against benchmarks, policies and best practices to provide the team with valuable information on how they are performing
- Conducting an internal analysis to review current effectiveness, identify gaps, needs and establish a bespoke plan for development. Consider capturing the following:
  - How many patients were part of the multidisciplinary care plan?
  - What worked well and what could have been improved?
  - Is there anything you would have changed?
  - How were the services delivered against the objectives set at the start of the MDT?
  - Are all members of the MDT clear about the purpose of MDTs (i.e., improving outcomes for patients)?
  - Do MDT members feel they have clear roles and responsibilities?
  - Does the MDT feel that they create integrated and holistic care plans which are cascaded to all relevant people involved in the care plan?
  - Do MDT members feel they have a lead practitioner who coordinates and leads the team?
  - Do MDT members feel that they have developed good relationships with all other professionals in the MDT?

Insights gained from various sources including expert meetings with HCPs, advisory boards, round tables and market research

Best practice case study: Norway

Small steps towards setting up a simple, multidisciplinary care team for patients living with short bowel syndrome with intestinal failure (SBS-IF)

The perception that only a perfect and formal multidisciplinary team (MDT) is effective can create a barrier for clinicians and internal staff who are trying to encourage other clinicians. This case study demonstrates the benefit and value of creating a pragmatic solution for a smaller practice with limited resources and budget to improve delivery of care and management of patients living with SBS-IF.

> The challenge:

Several barriers and obstacles were faced in setting up a MDT in a Norway clinical centre. Key stakeholders didn't grasp the full potential of a multidisciplinary team and voiced concerns about the time that would be required to set up processes and train team members.

Other clinicians were also hesitant and did not feel confident due to lack of knowledge and resources.

With just one gastroenterologist in the practice who wanted to break these barriers, this individual had to play multiple roles until the team was upskilled without being reimbursed for their time or having access to educational resources.

> The vision:

To build a basic, functional, multidisciplinary team by upskilling a small team of dieticians and nurses, involving co-workers and other physicians within the practice.

> Key steps to implementation:

- Drew upon learnings and experience from other more formal and structured MDTs in larger practices – within SBS-IF specialist centres in Europe and the USA
- Gained counsel from medical experts in SBS-IF and peers
- Conducted face-to-face meetings, lectures, lunch hour sessions and one-on-one upskilling sessions with co-workers, nurses and a dietician which provided information about benefits of a multidisciplinary approach and educated them around SBS-IF and the care required for these complex patients
- Assigned co-workers to manage patients, whilst knowing there was support in the background, which instilled a sense of accountability and required co-workers to fill in existing knowledge gaps
- The MDT team started with just one patient in the centre who needed differing support due to complex disease – the experience gained from managing this patient led to several more patient referrals

Continued >

Insights gathered from Dr Snorri Olafsson, Gastroenterologist, Norway

Best practice case study: Norway (cont'd)

Small steps towards setting up a simple, multidisciplinary care team for patients living with short bowel syndrome with intestinal failure (SBS-IF)

- Gathered qualitative patient data by asking key questions (e.g. urine output, stool urgency, how often they woke up at night) to measure success and improvement and asked patients to record the data informally, which had never happened before
- Carried out regular follow ups with patients and used electronic communications where possible, due to time constraints
- Discussed and wrote up several patient stories heard following discussions with peers, to build up a case around the need and value of a multidisciplinary approach to take to senior management to show the need for improved care and a MDT setup

> **Outcomes:**

- Following efforts by one gastroenterologist in 2014, the centre now (in 2020) has a team of eight, consisting of a dietician, nutritionist, nurses and other physicians. The efforts of the gastroenterologist who was determined to put into place practices he had seen elsewhere have resulted in a team which is more and more able to organise and operate itself
- The team of eight members now have a greater and improved understanding of SBS-IF and how to manage these patients and the process is still ongoing
- Having received positive feedback from patients, the hospital administration and clinicians who were initially concerned, realised and recognised that benefit could be gained through a multidisciplinary approach and discussions on future plans are ongoing

> **Key learnings:**

- The patient should be the focus of care and part of the core team, including shared decision making to upskill the patient, increase patient and physician satisfaction and improve overall patient outcomes
- Active participation of all team members and a willingness to learn is vital in sustaining a long-term and passionate team
- Leadership team support from the outset can help to create more positive and effective change but this may be faced with barriers
- Electronic correspondence between centres, clinicians and - where permitted - patients and clinicians, in order to share best practice, is greatly beneficial
- Access to SBS-IF disease educational materials (in local language if possible) would be very useful to educate HCPs on the benefits of a multidisciplinary approach and educate them further on the condition – this was a key need identified and an area Takeda could support
- Persistence is key; starting a multidisciplinary team alone requires passion and perseverance, but the patient feedback justifies the hard work

> "Don't give up – just keep doing it. If you know how to do it, then just do it"

> "You have to have a lot of personal enthusiasm and be willing to do this for a very long time"

Insights gathered from Dr Snorri Olafsson, Gastroenterologist, Norway

Best practice case study: Ireland

Establishing a centre of excellence

‘Centre of Excellence’ status can sometimes seem distant and unattainable. This case study sets out to demonstrate that through smart planning, careful evidence gathering and pragmatic decision making, care can be transformed across a health service, and a centre of excellence can be established to improve delivery of care and management of patients living with short bowel syndrome with intestinal failure (SBS-IF).

> The challenge:

There was no up-to-date data on SBS-IF patient numbers and established service provision for adult IF patients in Ireland was disjointed with no fully resourced multidisciplinary teams in place. The Irish Society for Clinical Nutrition & Metabolism (IrSPEN) had been calling on the Government to establish a national IF centre since 2013.

Patients were being distributed across different hospitals in small numbers and were not receiving the multidisciplinary care that was required to address the complex needs of the population. With the lack of a specialised adult centre, the pressure on the paediatric centre of excellence was increasing as patients needed to be transitioned eventually to a more comparable centre.

Unfavourable media reporting and patients who were at increased risk demanding for more specialised services, reinforced the need to urgently build a centre of excellence for adults in Ireland.

> The vision:

To build and establish a specialist unit for adults with IF, to include an experienced, multidisciplinary team

Continued >

Insights gathered from HCPs at St James’s Hospital, Ireland and LOC team

Best practice case study: Ireland (cont'd)

Establishing a centre of excellence

> **Key steps to implementation:**

- The hospital's Professor of Surgery conducted initial assessment of the key challenges and had open conversations about what worked successfully and what didn't
- There was a mutual recognition that St James' Hospital in Dublin, Ireland was better positioned than others to deliver as a centre of excellence, however efforts were made to ensure buy in from other centres
- The initiative was mainly driven by the hospital with support from IrSPEN, which provided additional credibility to the initiative
- Led by the hospital's Professor of Surgery who was well experienced, had a good understanding of the health system and good relationship with senior members of the hospital team
- The Professor of Surgery built a case that was presented to health executives with key information, including shortcomings of the current system (qualitatively and quantitatively), what a good centre of excellence looks like, barriers, funding required, and resourcing requirements
- The case was based around a national audit of intestinal failure prevalence which included an analysis of hospital admissions which was key to building the case
- The national audit showed that hospital admission was higher for intestinal failure patients but could not conclude whether this was due to higher rates of line infection (a key indicator of quality of care). The article was not published at the time but has been subsequently and is available at http://imj.ie/point-prevalence-of-adult-intestinal-failure-in-republic-of-ireland/ [Last accessed July 2020]
- Takeda Ireland supported the centre with funding and a national IF registry as confirmation of patient numbers was vital to ensuring adequate funding for service provision

> **Key learnings:**

- It is key to be acknowledged and recognised by centres as a potential candidate. If you are in a country where you have more than one good candidate, then that will need to be addressed appropriately
- Takeda teams shared data on the disparity of care from a policy programme
- Careful consideration should be given towards the involvement of appropriate hospital channels and check which route the case will need to go through as every hospital and health system will have different processes
- Working collaboratively as partners in facilitating optimum outcomes for patients was key to success
- The disparity between paediatrics and adults centre created the urgency amongst the hospital team. It has also given the opportunity to gather data needed to make the case for a more established and fully funded centre in the long term

Insights gathered from HCPs at St James's Hospital, Ireland and LOC team

Best practice case study: Austria

Establishing a high performing MDT

The multidisciplinary team at the Vienna General Hospital (AKH) was formed as a natural progression to provide support for SBS-IF patients and increase the standard of care around patients total parenteral nutrition (TPN). Before establishing the MDT, the team reviewed the interested disciplines and started to connect individuals. They also made observations about the patient journey, where patients tended to get lost in the treatment pathway, were not getting the right amount of TPN or overall nutritional support, and so the set-up of a MDT was a "no-brainer" in order to address these issues.

> The challenge:

Some of the key unmet needs identified before setting up a MDT in Austria was that there was a general lack of resources and HCPs didn't have enough time for their patients, especially to train them on subcutaneous self-injection. Patients found it extremely difficult to get appointments and the process of getting prescriptions was also time consuming.

> The vision:

To offer best-in-class support for patients, keep adherence high and provide individualised service based on individual patient needs.

> Key steps to implementation:

- The MDT in Vienna General Hospital (AKH) was established in 2016 and the Professor of Gastroenterology was the main point of contact. Other key members of the team included a dietitian, nurse, chief surgeon and junior surgeons
- Services offered to patients included:
  - Educational materials in the form of a starter kit, which included general information on SBS-IF, patient diary and emergency contact card
  - First point of contact for patients with a close feedback loop to the prescribing physician
  - Close monitoring of disease progression in collaboration with the prescribing physician
  - Frequent contact with regular meetings: weekly contact from for the first year; monthly contact in the second year and two follow up visits annually
- The MDT care model included the following steps that were coordinated by key members of the team:
  - Discussion of specific patients between MDT members
  - Starting patients on an appropriate treatment if required after discussions within the MDT
  - Ongoing case and care management by the gastroenterologist and dietologist

Continued >

Insights gained from the MDT at the Vienna General Hospital (AKH) in Austria

Best practice case study: Austria (cont'd)

Establishing a high performing MDT

> Critical success factors:

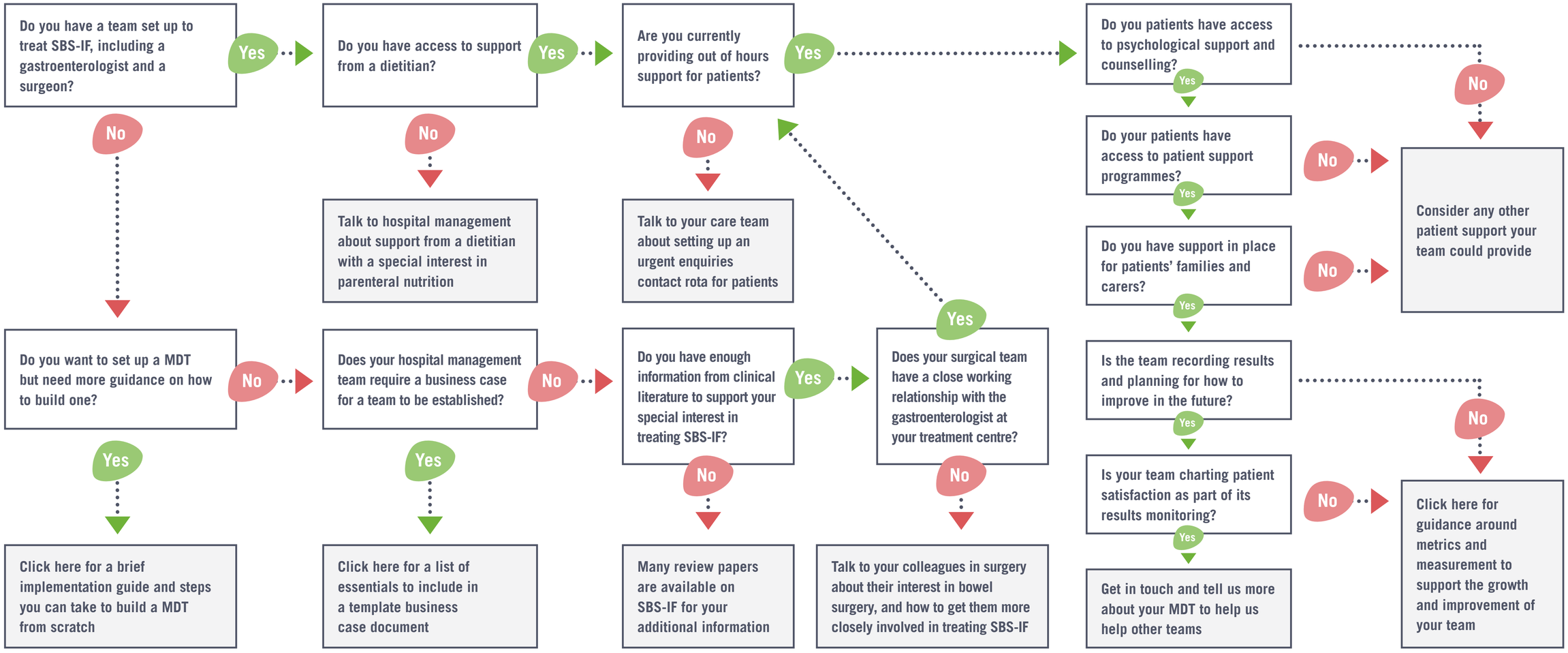
- Consistent case and care management: the lead nurse and dietologist are always connected and discuss next steps as soon as any irregularities are noticed
- Individual patient needs: the MDT aimed to provide individual focus on every patient and offered a consistent point of contact
- Highly engaged team: the dietologist is highly dedicated and available 24/7 for patients

> Key learnings:

- As SBS-IF is a rare disease, there was no formal communication between the surgeon, gastroenterologist and the dietologist. When establishing a MDT from scratch, setting up a formal time, at least once a month for the MDT to communicate and share knowledge about the patient will be beneficial (SBS-IF Board or included in the IBD Board)
- Due to different disciplines involved in the MDT, personalities and opinions can differ. Establishing a common purpose/goal, can help create a more unified approach

Insights gained from the MDT at the Vienna General Hospital (AKH) in Austria

What to do next to strengthen your team



Insights gained from various sources including expert meetings with HCPs, advisory boards, round tables and market research

Dario's experience with a multidisciplinary team (MDT) that offers specialist care and follow ups from one location

Dario was diagnosed with familial adenomatous polyposis (FAP) Gardner Syndrome in 1996 on his 27th birthday which later resulted in short bowel syndrome with intestinal failure (SBS-IF) in 2008. Before his diagnosis he viewed himself as perfectly healthy. Living with FAP Gardner Syndrome and later on with SBS-IF for nearly 25 years brought about considerable challenges but with the help of his care team, Dario has been able to lead a fulfilling life with his three children and wife, as well as travelling extensively to Africa to follow his passions.

Dario's diagnosis journey

Dario's illness began when he noticed blood in his stool. At first, he thought it may be hemorrhoids, but after seeing a specialist, he was told that he needed to have emergency surgery to have his bowel removed. The need for surgery shocked him, as aside from the blood he didn't have any symptoms – he had no pain and felt fit and young. His life with Gardner Syndrome was relatively smooth until 2002, when he started to have other problems. He suffered from a number of tumors in his bowel, suggesting an ongoing underlying problem. After further surgery in 2003, in 2008 an X-ray showed more tumor growth which required extensive surgery and resulted in complete removal of his bowel resulting in the SBS-IF which deteriorated his health further. Following this, Dario went onto total parenteral nutrition (TPN), which helped him gain control over his life again. Over the years, there have been lots of hurdles, including a septic embolism, minor surgeries, and a case of jaundice while he was on TPN.

Dario's care team

Living in the Swiss Alps, Dario visited smaller local hospitals for simple procedures, such as changing his port-a-cath system and visited the university hospital for more complex surgeries that specialize in his condition.

Dario appreciates the importance of the surgeons who have been a part of his care but thinks that the MDT that surround them and follows up is, if anything, more important. He sees great value in the surgeon being at the same hospital so that the gastroenterologist and the surgeon can continue to communicate with each other about his illness and thinks this is very important for any patient.

Dario believes nurses are also a very important part of the MDT and underlines the importance of strong lines of communication between doctors and nurses given that nurses are often the ones doing the day to day administration of care.

Continued >

Dario's experience with a multidisciplinary team (MDT) that offers specialist care and follow ups from one location

Education is also a key part of managing SBS-IF and Dario would encourage anyone diagnosed with the illness to seek out as much information as they can. From the outset, Dario equipped himself with information about the illness by reading research papers and tapping into his network of doctor-friends. He appreciates his gastroenterologist exchanging key educational information around his condition from medical literature, congresses and university lectures.

In addition to the team dealing directly with his treatment, Dario has also seen a psychologist to support his mental health and to deal with the impact of the condition on his life. But this was not extended to his family which could have been a helpful addition to his care.

Dario's words of advice

His main piece of advice to health professionals who are part of a MDT would be to invite families to meetings and take them along in the journey; to not look at a patient as an individual but as a group of people.

> "After looking at different approaches in the hospitals that I was cared for, I realised that for my condition, it was very important that different doctors and disciplines communicate with one another"

> "As a patient, especially with this illness, educating yourself and playing your part alongside your MDT is essential"

Kathleen's experience with a multidisciplinary team (MDT) that recognises her individual needs

Kathleen was diagnosed with Crohn's disease in 1985 at the age of 15, at a time when there was very little information about the condition and no treatment available in Belgium. As a 15-year old diagnosed with a chronic condition, it was going to be a long and difficult journey for Kathleen. She had to put on hold her studies as a beautician. Later on, after starting her own beauty salon, she had no choice but to also give that up after Crohn's took over her life completely.

Kathleen's diagnosis journey

In the summer of 1992, Kathleen was told that the condition of her bowel had worsened so she needed a colostomy. She couldn't believe that she had to undergo a colostomy at the age of 22. She had the surgery in a small local hospital but things got worse after it went wrong. She spent six months in hospital, and in January 1993, she left having had an ileostomy. This is the point at which, she started her life with short bowel syndrome with intestinal failure (SBS-IF).

Kathleen's care team

Kathleen received treatment and care at two hospitals after her ileostomy. Although Kathleen's first hospital provided excellent care for 15 years, she decided to change her hospital after she felt that the core team had changed and she ended up feeling more like a number than a person.

Since 2009, Kathleen has been at a different hospital and is extremely satisfied with the team that surrounds her. She feels like she is being listened to as an individual; and is part of the decision-making process, as her gastroenterologist and surgeon spend time talking to her to make sure she is comfortable with her care decisions

What Kathleen values the most in her current care team is the fact that everyone from her doctor to the nurses, know her and her specific needs very well. It makes her feel that she is being listened to. She also values the open lines of communication she has with her gastroenterologist, nutritionist and dietician, who are available via phone/email anytime she needs them.

> "I don't feel the need to explain myself every time because they know me and my needs so well"

Kathleen's words of advice

Kathleen's advice to other patients is to not wait to ask burning questions, and to respect yourself as an important part of the decision-making team. When she was younger, she used to feel like the doctors were in charge and she had to defer to them, but she now feels more in control and has an important say in her treatment and care plans.

> "I felt like I was being treated like a human being and not just a number. They listened to me and I felt like they knew my case and have looked into it thoroughly"

Petra's experience with a multidisciplinary team (MDT) that maintains consistent and open lines of communication

Petra's journey with short bowel syndrome with intestinal failure (SBS-IF) began in 1996, when she had cancer in her bowel and bladder. She had chemo and radiotherapy, as well as several resections, until one year later, a significant portion of her bowel was removed. She was not able to consume food orally for five months, until eventually she could manage a bouillon and a biscuit. In 1998, Petra started having her TPN at night, first five, then six and now for years, seven nights a week. She has now been dependent on it for nearly 25 years. She has since been able to organise her life around SBS-IF. Petra enjoys swimming, hiking and biking in the summer, reading and visit exhibitions in the winter.

Petra's care team

Petra had her first surgery in a non-university hospital in Belgium, but because of another tumour that developed, she was transferred to a university hospital. The care in the non-university hospital was very good, but with the establishment of a MDT in the university hospital, she changed to receive specialist care for her condition. She feels that the TPN is highly tailored to her needs, which is very important for her. Her current team is comprised of a gastroenterologist who is specialised in TPN, a nurse and a dietitian. Her gastroenterologist leads care decisions, the nurse specialist does most of the technical care administration and patient education, and the dietitian helps her balance - if necessary - her food intake.

What Petra values most in her care team is their high level of responsiveness, alongside their knowledge and understanding of her condition. Whilst the HCPs lead the clinical decisions, they actively listen to Petra's needs and concerns. It gives her the reassurance that her care is being managed well and that they are open to her suggestions. She also has total confidence in her lead gastroenterologist and does not feel the need to resort to the internet for additional information or help as he provides her clarity and confidence in their decisions.

While Petra doesn't have family who the care team need to interact with, she does appreciate they provide social counsel and life guidance. She has to monitor her liver and kidney health closely and she feels well supported in this respect.

> "Even though they are very busy, my team are very receptive to messages and it reassures me that I can call them whenever I need them"

Petra's words of advice

Although Petra is very satisfied with the care she is currently receiving, her advice would be to include a person in the MDT who could support the patient with legalities and the processes around funding/social benefits, as well as providing guidance on the different rights of patients as she has had to seek this information elsewhere herself, which is difficult as it is a complicated matter, with many rules.

It is good to know that a patient community exists, Petra enjoys her interaction with them and thinks it is good to be in contact with other patients across different countries to share experiences.

> "I have learnt to live with it [SBS-IF], and with the help of my team, I try not to let it overwhelm me so I can live a normal life"

Sebastian's experience with a multidisciplinary team (MDT) that encourages knowledge building

Sebastian's story began when he was diagnosed with bowel cancer in 2016 at the age of 35 when he was young, full of energy and just about to go on a business trip. It came to him as a surprise as he didn't present with any symptoms until 3-4 weeks before his diagnosis. Sebastian underwent surgery to resect part of his bowel but because the surgery wasn't a success, he had to go in for four follow up surgeries after which more of his bowel was removed. He didn't feel like he was part of any treatment decisions over the course of his surgeries, as, in his mind there were no decisions to make.

Sebastian's care team

After spending almost five months in hospital, Sebastian was eventually connected to total parenteral nutrition (TPN), and because his hospital was not specialised in this area, he was transferred to a new and larger hospital with more knowledge of how to care for SBS-IF patients. The first hospital helped him with his diagnosis and surgery, whereas the second hospital helped him cope with SBS-IF with a specialist team including a dietician, who was able to provide Sebastian with training around how to live with parenteral nutrition, as well as support for his family.

After reading up and researching about his condition however, Sebastian started to find the treatment advice and the equipment used slightly outdated. After finding a helpful patient support group, Sebastian moved to a third hospital within Poland, where he felt the doctors were more knowledgeable and abreast of current developments in SBS-IF by being involved in international meetings, lectures and exchanging information with other doctors around the world.

Sebastian's current care lead is an anesthesiologist (specialised in bowel surgery) and a dietitian who he sees regularly. He also has access to specialist nurses who is not only responsible for his bloods and other important tests, but also imparts useful training to help him manage his condition. He finds the team very supportive of his needs, as he often has to travel for business, and they, along with the pharmacy team, help to ensure he is equipped and able to do this.

Sebastian feels his team is very supportive of patients' individual needs and lifestyle choices – he explained that if he wanted to pursue a sport, they would help him adjust his nutrition and medication to allow this. He enjoys a strong relationship with his team, who not only share and exchange knowledge from important medical meetings but also encourage him to build his own knowledge by inviting him to meetings and other educational events – as someone interested to know more about his condition, Sebastian values this aspect the most in his care team.

Sebastian's words of advice

Due to his experience, Sebastian would advise patients living with the condition to read, explore and find other options if they are not happy with their current team or set-up.

> "I feel my MDT has the most up-to-date knowledge and because of this I feel much safer and reassured that they will suggest solutions that work for me"

> "They specifically design nutrition plans for me by adapting each ingredient as per my body and that has improved results tremendously"

References

1. Parrish C.R., *et al.* Managing the Adult Patient With Short Bowel Syndrome *Gastroenterology & Hepatology.* 2017;13(10):600-608.

2. National Organization for Rare Diseases (NORD). Short Bowel Syndrome. Available at https://rarediseases.org/rare-diseases/short-bowel-syndrome/. Last accessed August 2020.

3. Baars JE, *et al.* Patients' preferences regarding shared decision-making in the treatment of inflammatory bowel disease: results from a patient-empowerment study. *Digestion.* 2010;81(2):113-119.